Joint MPH Program

University of Gondar and Addis Continental Institute of Public Health

Assessment of the Magnitude and Factors Associated with Loss to Follow up in the ART Program of St Peters Hospital, Addis Ababa

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Abbreviations

AA	**Addis Ababa**
ACIPH	**Addis Continental Institute of Public Health**
AHRI	**Armauer Hanson Research Institute**
AIDS	**Acquired Immunodeficiency Syndrome**
ALERT	**All Africa Leprosy Education Rehabilitation and Training Center**
ANC	**Anti Natal Care**
ART	**Anti Retroviral Therapy**
ARV	**Anti Retrovirals**
ASW	**Adherence Support Workers**
CBT	**Cognitive Behavioral Therapy**
CCF Canada	**Christian Children's fund**
CDC	**Center for Disease Control**
CI	**Confidence Interval**

ENAHPA **Ethiopian North American Health Professionals Association**

ETB **Ethiopian Birr**

FHAPCO **Federal HIV/AIDS Prevention and Control Office**

FNA **Fine Needle Aspiration**

HAART **Highly Active Anti Retroviral Therapy**

HCT **HIV Counselling and Testing**

HH **House hold**

HIV **Human Immunodeficiency Virus**

Hosp **Hospital**

HR **Hazard Ratio**

IRB **Institutional Review Board**

IRR **Incidence Rate Ratio**

JAMA **Journal of American Medical Association**

JHU-TSEHAI: **Johns Hopkins University-Technical Support for Ethiopian HIV/AIDS ART Initiative**

LTFU **Lost to Follow Up**

M & E **Monitoring and Evaluation**

MoH	**Ministry of Health**
NGO	**Non Governmental Organization**
OR	**Odds Ratio**
PLH	**Person Living with HIV**
PMTCT	**Prevention of Mother to Child transmission of HIV**
RCT	**Randomized Controlled Trial**
RR	**Relative Risk**
SPSS	**Statistical package for Social Sciences**
UoG	**University of Gondar**
USAID	**United States Agency for International Development**
WHO	**World Health Organization**

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Abstract: Background: As much success has been made internationally and nationally on ART rollout and reduction of morbidity and mortality, adherence and long term retention of patients in treatment programs (preventing loss to follow up) has remained a challenge.

Objectives This study aimed to assess the magnitude as well as factors associated with loss to follow up in the ART program of St Peters Hospital, Addis Ababa. More over it also described the perspectives of patients on why they discontinue ART.

Methods: a cohort of patients who started ART in St Peters Hospital from Megabit 1998 EC (March 2006) to Hidar 2000 EC (November 2007) were retrospectively followed. Data was collected using a pre tested abstraction form from ART intake and follow up national forms on demographic variables, living condition, behaviour, clinical variables and Outcome. The qualitative part used in depth interview of patients and key informants to describe their perspectives.

Results: 1095 patients contributed to 1234.36 person years of follow up during which 370 LTFUs occurred. Incidence of LTFU was 300 per 1000 person years (CI: 269, 330). Median time of loss to follow up is 59 days, (IQR: 0.00, 193). Independent predictors of loss to follow up are age (p=.014, HR=.98), functional status (p=.044, HR=.54), baseline CD4 count (p=.037, HR=.998) and Understanding of HIV disease (p=.018, HR=3.325). Reasons for discontinuation of ART include going to holy water, poverty and lack of food, going to the regions for “personal” reasons, and substance use especially among the youth and young adults.

Conclusion and recommendation: LTFU from the ART program is high and influenced by modifiable factors. High priority should be given to address the problem of high LTFU. This should include expanding the ART-Holy water initiative and recognition and if possible addressing the spiritual needs of patients at Health facilities. ART treatment programs should be coupled with income generation and livelihood programs for a short term solution of poverty and foodinsecurity.

Introduction

An estimated 33.2 million people worldwide were living with HIV, with 2.5 million new infections and 2.1 million deaths to AIDS in 2007 alone [1]. Sub- Saharan Africa remains the worst affected region in the World with a little more than one-tenth of the world's population but home to more than two third of people living with HIV in the world and it represents 77% of women with HIV, 79% of AIDS deaths, and 92% of the world's AIDS orphans.(1).Ethiopia is among countries highly affected by the epidemic with estimated 1,037,267 people living with the virus resulting in 58,290 HIV related deaths and 125,147 new infections, adult HIV incidence of 0.27% and national HIV prevalence of 2.2% in 2008. The epidemic is more concentrated in urban areas like Addis Ababa which has a prevalence of 7.9%, 171,722 people living with HIV, 21,732 new infections and adult HIV incidence of 1.49% in 2008, [2].

With the advent of HAART, HIV has become a chronic manageable disease. It is transformed from being a death sentence to a treatable condition. It is also shown that ART is equally effective in resource poor settings as in rich countries. A meta analysis of outcome of ART in developing countries found that the proportion of patients with undetectable viral load was 0.697 (95% CI, 0.582–0.812) at month 6 and 0.573 (95% CI, 0.432–0.715) at month 12 of ART and it concluded ART treatment programs in resource-poor settings have efficacy rates similar to those reported for developed countries (3).

National and international commitments have made ART available even to the poorest and hardly hit by HIV areas like sub Saharan Africa. Ethiopia is among the beneficiaries of these initiatives. After WHO's '3 by 5' initiative in 2003, many countries in sub-Saharan Africa have established national antiretroviral treatment (ART) programmers. By mid-2005, the WHO target had already been overtaken by an even more ambitious aim. In July 2005, the G8 group of industrialized countries committed to the goal of achieving 'As close as possible to universal access to treatment for all those who need it by 2010' (4)

Since 2005, when free ART has been started in the country, over 170,000 people have accessed it by November 9, 2008 (5). But 45,239 of the 170,870 who ever started ART in the country (26.5%) are not currently on treatment. This figure for Addis Ababa public sector is 41,075 ever started and 30,821 currently on treatment, an attrition rate of 25.0% (5). Much of the attrition from the treatment program is attributed to loss to follow up and mortality. This much attrition from treatment especially due to loss to follow up is concerning as it facilitates emergence and spread of resistant viruses which is more difficult and costly to treat (currently ten times more expensive than 1st line ART) and with more unfavourable outcomes. Many studies have demonstrated that emergence of any resistance was associated with increased risk of mortality (6).

More over high rates of loss to follow up distort the real outcome (effectiveness) of the program as it is difficult to know what really happened to those lost from follow up. In a cohort study in Of 68 patients initially categorized as lost, over half (58.8%) were confirmed dead after tracing. Patient tracing resulted in reporting of significantly lower survival rates when death was used as

the outcome and losses to follow-up were censored. In addition, important risk factors of mortality/survival will be missed when there is high rate of loss to follow up (7).

Hence there is big concern among all stakeholders involved. The Government of Ethiopia has initiated some measures to address this problem (8). But much research has focused on day to day adherence than long term retention of patients in programs. Hence there is little knowledge on which kind of patients are more likely to be lost to follow up and we do not know why it happens so. This study tries to contribute to filling these gaps in knowledge.

Literature review

Levels of Adherence in developing and developed countries and factors associated with it

Delivery of ART to Africa has passed through many debates and controversies. In 2001 the chief of the United States Agency for International Development (USAID), Andrew Natsios, gave this justification to the US Congress for why the agency opposed ART to Africans with HIV. "…Africans do not know what watches and clocks are. They do not use western means for telling time. They use the sun. These drugs have to be administered during a certain sequence of time during the day and when you say take it at 10:00, people will say what do you mean by 10:00?". Many officials from governments as well as international organizations tried to justify withholding ART from Africans on the basis of weak infrastructure, lack of human resources and more importantly patient's inability to take medications appropriately (poor adherence) (9).

But two systematic reviews prove these speculations were mistaken. Despite their continent's poverty, and schooled or not in time keeping, Africans overcome these barriers and are better than North Americans at taking ART. A meta analysis published in JAMA included Thirty-one studies from North America (28 full-text articles and 3 abstracts) and 27 studies (9 full-text articles and 18 abstracts) from sub-Saharan Africa. A pooled analysis of the North American studies (17 573 patients total) indicated a pooled estimate of 55% (95% confidence interval, 49%-62%; I2, 98.6%) of the populations achieving adequate levels of adherence. The pooled analysis of African studies (12 116 patients total) indicated a pooled estimate of 77% (95% confidence interval, 68%-85%; I2, 98.4%) (10-12).

There are also studies which show adherence in Africa is as challenging as it has been in the West. Another review published in AIDS concluded adherence rates in Africa are quite variable and often poor (13).

Adherence is a complex issue and is influenced by several factors. Several behavioral studies were conducted to establish a model or predict adherence. One study tried to develop a model for adherence in adolescents. In the study Predictors of adherence in the Generalized Estimated Equation (GEE) were: high perception of self-efficacy (OR=1.68; 95%CI 1.27-2.22), positive attitude towards taking medication (OR=1.56; 95%CI 1.18-2.06), not living alone (OR=1.47; 95%CI 1.04-2.08) and being a male (OR=2.81; 95%CI 1.47-5.34) (14).

In the French APROCO cohort study, after multiple adjustments for other related factors, such as younger age, alcohol consumption and poor housing conditions, the number of self-reported

lipodystrophy symptoms was independently associated with adherence failure indicating the role of ARV side effects on adherence (15).

A study in Mississippi sought to gain understanding of barriers to adherence interviewed Seventy-two patients who missed a dose of ART medication over the last three days endorsed the top five reasons for missing a dose as: (1) not having the medication with them, (2) sleeping through the dose time, (3) running out of the medication, (4) being busy with other things and (5) other reported barriers were fairly consistent across different groups, although women and those classified as having moderate to severe depressive symptoms reported different patterns of adherence barriers (16).

There is also several studies form Sub Saharan African countries on levels of and factors influencing adherence. a study from a rural missionary Hospital in Zambia reported At least 95% adherence to be documented for 83.7% of the patients in their first months of ART. Travel-related factors did not predict adherence in this study (17).

Another prospective study was conducted in Jimma Hospital, South East Ethiopia to investigate the rate and predictors of adherence to antiretroviral therapy. A total of 400 and 383 patients at baseline (M0) and at follow up visit (M3) respectively were interviewed. Self-reported dose adherence in the study area was 94.3%. The rate considering the combined indicator (dose, time and food) was 75.7%. Within a three month follow up period, dose adherence decreased by 2% and overall adherence rate decreased by more than 3%. Adherence was common in those patients who have a social support (OR, 1.82, 95%CI, 1.04, 3.21). Patients who were not depressed were two times more likely to be adherent than those who were depressed (OR, 2.13, 95%CI, 1.18, 3.81). However, at the follow up visit, social support (OR, 2.42, 95%CI, 1.29, 4.55) and the use

of memory aids (OR, 3.29, 95%CI, 1.44, 7.51) were found to be independent predictors of adherence. The principal reasons reported for skipping doses in the study were simply forgetting, feeling sick or ill, being busy and running out of medication in more than 75% of the cases (18).

An observational analysis of an open multicenter randomized HIV/AIDS management trial in Uganda and Zimbabwe found that good adherence increased from 87%, 4 weeks after ART initiation, to 94% at 48 weeks, but only 1454 (49%) patients achieved good adherence at every visit in the first year. Complete adherence was associated with 0.32 greater reduction in $\log_{10}$ viral load (95% confidence interval 0.05, 0.60 P = 0.02) and was independently associated with higher baseline CD4 count, starting ART later in the trial, reporting a single regular sexual partner, clinical center, and time on ART (19).

A study in Tanzania, Uganda and Botswana using a rapid appraisal method found out that related costs (e.g. transport expenditures, registration and user fees at the private health facilities, and lost wages due to long waiting times) as main obstacles to optimal adherence. Side effects and hunger in the initial treatment phase are an added concern (20).

In A cross sectional Quant-Qual study in Botswana, Principal barriers to adherence included financial constraints (44%), stigma (15%), travel/migration (10%), and side effects (9%). On the basis of logistic regression, if cost were removed as a barrier, adherence is predicted to increase from 54% to 74% (21).

A meta analysis of 37 qualitative studies and 47 studies using a quantitative methodology (surveys) in developed and developing countries found that Important barriers reported in both

economic settings included fear of disclosure, concomitant substance abuse, forgetfulness, suspicions of treatment, regimens that are too complicated, number of pills required, decreased quality of life, work and family responsibilities, falling asleep, and access to medication. Important facilitators reported by patients in developed nation settings included having a sense of self-worth, seeing positive effects of antiretrovirals, accepting their seropositivity, understanding the need for strict adherence, making use of reminder tools, and having a simple regimen (22).

Loss to follow up

But much attention has been on patient's day to day adherence than to retention in the treatment programs which is a pre requisite for any adherence. Many research and published data focus on describing the outcomes and adherence levels of those retained excluding those lost to follow up. Attrition from antiretroviral treatment programs is generally divided into four categories. The two most common are (1) the death of the patient—several studies have reported high rates of early mortality—and (2) ''loss to follow-up,'' a catch-all category for patients who miss scheduled clinic visits or medication pickups for a specified period of time. (3)Some patients remain in care but stop taking ARV medications. Others transfer to other facilities and continue on ART (4). The second category, loss to follow up is the focus of this study.

Unmatched case control study conducted in Jimma Hospital to determine prevalence and factors associated with defaulting from antiretroviral treatment (ART) in Jimma, Ethiopia indicated that Reasons given for loss to follow up were loss of hope in medication, lack of food, mental illness, holy water, no money for transport, and other illnesses. Moreover taking hard drugs (cocaine, cannabis and IV drugs), excessive alcohol consumption, being bedridden, living outside Jimma

town and having an HIV negative or unknown HIV status partner were associated with defaulting ART (23).

A study in Zambia, Lusaka conducted community based follow up of late patients via home visits. Between May and September 2005, home-based caregivers were dispatched to trace 1,343 patients with missed appointments. Of these, 554 (41%) were untraceable because the provided address was invalid, the patient had moved or no one was at the home. Of the remaining 789, 359 (46%) were reported to have died. Only 430 (54% of those traced, 32% overall) were contacted directly and encouraged to return for care. The likelihood of patient return was higher among traced patients in crude analysis (relative risk [RR]_2.5; 95%CI_1.9_3.2) and in multivariable analysis controlling for baseline body mass index, sex and CD4_count550/mL (adjusted RR_2.3; 95%CI_1.7_3.2). However, the process was inefficient: one late patient returned for every 18 home visits that were made. Reasons for missed visits were provided in 271 of 430 (63%) of the patients who were successfully traced. Common reasons included feeling too sick to come to the clinic, travelling away from home and being too busy (24).

In a South African study Non death program losses (loss to follow-up, 2.3%; transfer-out, 1.9%; relocation, 0.7%) were not associated with immune status and were evenly distributed during the study period (25).

A retrospective study was conducted in Johannesburg to assess the rate of and factors associated with loss to follow up. This study found that of 1631 adult patients studied, 267 (16.4%) discontinued follow-up during the study period. Gender, ethnicity, and age were not predictive of loss to follow-up. Of those discontinuing follow-up, 173 (64.8%) were successfully traced. Death accounted for 48% (n = 83) of those traced (26).

Another study did a systematic review of patient retention in ART programs in sub-Saharan Africa to see patient retention rates. It reviewed 32 publications reporting on 33 patient cohorts (74,192 patients, 13 countries). For all studies, the weighted average follow-up period reported was 9.9 mo, after which 77.5% of patients were retained. Loss to follow-up and death accounted for 56% and 40% of attrition, respectively. Weighted mean retention rates as reported were 79.1%, 75.0% and 61.6 % at 6, 12, and 24 mo, respectively. Of those reporting 24 mo of follow-up, the best program retained 85% of patients and the worst retained 46% (27).

Interventions for adherence

Many interventions have been tried to improve adherence in the African as well as in developed countries settings.

A randomized multi site controlled trial evaluating the effect of cognitive behavioural adherence intervention concluded that the effects of the cognitive behavioral intervention on adherence were modest and transient, and no effects were observed on viral load or CD4 cell count (28).

Findings from an RCT to evaluate effect of proactive telephone support to improve adherence indicated that customized, proactive telephone calls have good potential to improve long-term adherence behavior and clinical outcomes (29).

A study was conducted in 4 US cities: Los Angeles, CA; Milwaukee, WI; New York, NY; and San Francisco, to evaluate effect of CBT on adherence found significance difference in rates of

reported adherence between intervention and control participants at months 5 and 15, corresponding to the assessments after the Stress, Coping, and Adjustment module (5-month time point) and after the Health Behaviors module (15-month time point). The relative improvements among the intervention group compared with the control group dissipated at follow-up (30).

Another study in Tanzania to assess the effect of food supplementation on ART adherence found that food supplementation was associated with better adherence to therapy. Two hundred fifty-eight of 366 (70%) patients in the food group achieved a medication possession ratio of 95% or greater versus 79 of 166 (48%) among controls (relative risk = 1.5; 95% confidence interval: 1.2 to 1.8). This finding was unchanged after adjustment for sex, age, baseline CD4 count, baseline World Health Organization stage, and baseline hemoglobin. But it did not observe a significant effect of food supplementation on weight gain or CD4 cell response (31).

Another study in Zambia assessed the effectiveness of ‘adherence support workers’ (ASWs) in adherence counseling, treatment retention. ASWs were recruited fro the community, trained, deployed and their effect was assessed with a qualitative as well as a quantitative approach. Findings include Quality of adherence counseling by ASWs was comparable to HCWs after their introduction. The findings also suggest that the deployment of ASWs helped reduce waiting times for adherence counseling. Loss to follow-up rates of new clients declined from 15% to 0% after the deployment of ASWs and also helped in addressing inadequate human resources at health facilities (32).

Objectives of the Study

General objectives

To determine magnitude of loss to follow up in the ART program in St Peters Hospital, Addis Ababa and factors associated with it.

Specific objectives

1. To calculate the incidence of loss to follow up in the ART program of St. Peters Hospital
2. To describe the perspective of patients on why they discontinue ART
3. To assess factors influencing loss to follow up in the ART program of St Peters Hospital, Addis Ababa

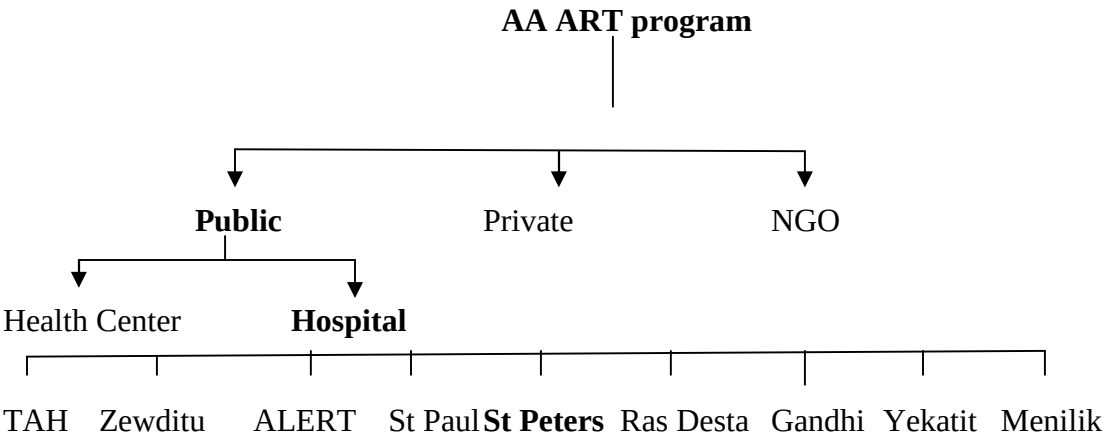
Methods

Study Area

Addis Ababa is located in the heart of the country in an area of 540 square kilometers. It is situated between 9 degrees latitude and 38 degrees east longitude in the plateau that stretches at the range of 2,200-2,800 meters of latitude above sea level. The structure of the organs of power of the City includes the City Government, 10 Sub-Cities & 99 Kebeles. The population of AA is 2.74 million; females constitute 52.36% of the population. Children Under one year of age constitute 1.33% of the total population, while under five children account for 7.16%. Women of childbearing age are 34.65 %.Average House hold size is 4.1. (Central Statistical Authority, 2007 National census first draft report).

Addis Ababa Health bureau is responsible for both curative and preventive health care of the city under which there are 5 hospitals, 1 Public health laboratory and 1 Nursing school. There are also 10 sub-city health departments, which are directly accountable to their respective sub-city administration. Totally there are 38 hospitals in the metropolis of which 5 are under AARHB, 5 under federal ministry of health, 2 under NGO's, 3 are Defense and Police Hospitals and 23 are private Hospitals. There are 27 health centers of which 24 are owned by the city administration, 2 by NGO's and 1 by the public. The potential health service coverage in Addis with regard to geographical accessibility is 100%.The primary health care units (Health center) availability indicator, at a rate of 1 health center for 75,000 populations. (Addis Ababa City Government Millennium Anti AIDS Campaign one year Plan).

St Peters Hospital is selected because it has adequate pool of patients, its data collection and monitoring and evaluation system is good and tracing of patients is regularly done to ascertain their outcomes.



St Peters Hospital: The Hospital has Outpatient and Inpatient departments and diagnostic and drug supply services (pharmacy, laboratory, radiology and pathology, FNA). The outpatient and inpatient have merged in 2000 and are under a single administration under Federal MoH and named St Peter TB Specialized Hospital. The outpatient section of St Peters Hospital provides TB screening, diagnosis and referral, Paediatrics, HCT/ART. The Hospital has three main objectives: health services, training and research. It has a training and research unit staffed by a nurse and public health professional. Although the Hospital gives general medical services (general internal medicine, paediatrics and now MCH), much of the patients visiting the OPD come for treatment of chronic cough (personal communication).

Free ART is started in the outpatient department on Meskerem 11, 1998 (September 21, 2005) to serve a catchment population of 254,972 residents of Addis Ketema sub city (National Census 2007). By Hidar 30, 2001 E.C 2175 patients have already started ART and 2952 have been enrolled into chronic care. The Hospital recently launched ANC and PMTCT service (Monthly report, St Peters Hospital ART department).

Study design

This study is conducted in mixed quantitative and qualitative methods.

I. Quantitative part:

A retrospective cohort study from existing data in clinic records (patient charts) and registers in St Peters Hospital ART clinic to determine the incidence of loss to follow up, risk factors for loss to follow up and the average or peak time of loss from follow up. Cohorts are patients who started ART in St Peters Hospital from Megabit 1998 E.C (March 2006) to Hidar 2000 E.C (November 2007). Patients were classified based on their disclosure status as exposure category and incidence of LTFU compared between those disclosed at baseline and those who didn't. Other baseline characteristics are also treated as secondary independent variables and analyzed.

Study Population and sampling

The source population is patients who started ART in the ART program in St. Peters Hospital, Addis Ababa. The Study population is cohort of patients who started ART in St Peters Hospitals ART clinics from Megabit 1999 E.C (March 2006) to Hidar 2000 E.C (November 2008). 1368 adult patients have started ART in St Peters Hospitals ART clinic during this time. Excluding early Transfer outs from Ever started for the Hospital, we found 1175 study candidates making adequate sample for the study. (Monthly report, Hidar 2000 E.C, St. Peters Hospital). Cohorts were followed until an event occurs (loss to follow up) or censored by the last actual visit date if not lost to follow up. Only 1095 patients fulfilled the selection criteria and are included in the analysis. Some charts could not be located or the information is too incomplete to be included in the analysis.

Sample size

Quantitative Part: retrospective cohort study

Assuming prevalence of loss to follow up to be 20%, with 95% confidence interval and 3% degree of precision, a sample of **629** patients is required to estimate the magnitude (cumulative incidence) of Loss to follow up. With the actual finding of frequency of loss to follow up of 33%, a sample of 1095 is more than adequate for this objective. It can estimate the incidence of loss to follow up with a better precision.

To assess for factors associated with LTFU, To detect a relative risk of 1.5 with an 80% power and 95% confidence, a sample of 626 subjects (313 exposed and 313 unexposed) is required (taking 1:1 ratio of exposed and not exposed) or 714 , of which 476 unexposed and 238 exposed is required (taking a 1:2 ratio of exposed and not exposed). For those independent variables with rare frequency (less than 10%), eg: perceived stigma, the sample can detect only a relative risk of 2.00, and with a 1:4 ratio of exposed : unexposed. With this assumption the sample requirement will be 390, 312 unexposed and 78 exposed. If the exposure group is less than 78, the statistical test will not have adequate power. The final sample size required for all the objectives was 714**.**

Inclusion criteria

- Enrolled and started ART in St. Peters Hospital ART clinic ("Transfer in" s are excluded)
- Age >=14 at time of enrolment
- Demographic and clinical data consistent and adequately complete in the ART chart and/or Hospital and pharmacy chart
- ART chart retrievable
- Started ART at least 6 months before date of data collection

Data collection and Procedures

Data was collected using a pre tested abstraction form (see annex) from ART intake and follow up national forms which are completed at time of enrolment (first visit to the clinic), and every time patient comes to the clinic respectively. Collected data include

- Demographic variables: age, sex, residence, education level, religion, employment, marital status,
- Living condition: number of rooms, House hold size
- Behaviour : drug, khat and alcohol use, disclosure of HIV positive status, perceived stigma or other adherence concerns, sexual behaviour
- Clinical variables: WHO clinical stage, CD4 count at start of ART, Weight and height, functional status, Date of ART start and initial ART regimen, last actual visit date, last appointment date, 6 month weight, 6 month CD4, 12 month weight, 12 month CD4
- Outcome was ascertained from the chart and ART register or pharmacy register (LTFU or still on follow up, death or Transfer out). For all, last actual visit date is taken us date of the outcome.

Data collection was done by trained ART clinic data clerks and ART nurses, who have at least a three days training on M & E of ART and experienced in using the forms. Moreover those with at least one year of experience in using the forms were selected. All data collectors were given training and orientation on purpose of the study, the abstraction form,

source of the data before embarking into data collection. Data abstraction form was initially pilot tested and refined before final use. General Hospital chart, pharmacy chart, ART and pharmacy registers were used as complementary sources, as needed. The data collection process was supervised by the investigator.

Data quality control

All the above data is routinely collected for routine care purposes on standard formats. When a patient is confirmed HIV positive and reports first to the Hospitals ART clinic, a General Hospital chart and ART chart is issued.

In the first visit of routine care, information will be collected by data clerk, ART nurse and ART physician using the standard 7 page intake forms. The forms include: Form A=Patient registration form (socio demographic information), form B= past medical/treatment History, form C=General condition/physical exam form, form D= Clinical review (WHO staging and clinical evaluation), form E= social assessment form (employment, living condition, supportive care, disclosure, issues/concerns) F=ART adherence counselling form (Knowledge on HIV, sexual behaviour, substance use, adherence concerns) and form G=ART assessment and plan.

The follow up form has data on patient identification, nature of visit (scheduled or unscheduled), date of visit, weight, pregnancy and/or Family planning status, functional status (working, ambulatory or bed ridden), WHO stage, TB screening assessment, Opportunistic infection, cotrimoxazole prophylaxis or medications, ART regimen, adherence level, side effects, lab data (CD4 count Hgb, ALT/AST) and next visit date.

All the data to be collected is obtained from the ART chart, intake and follow up forms. The monitoring and evaluation process and routine recording and reporting is regularly assisted and quality assisted by partner NGO (JHU-TSEHAI). Hospital and Pharmacy chart and registers are used as complementary in case of incomplete data on ART chart and for rechecking random sample of data. Data on the above variables was extracted and entered into a computer using Epi Info 3.4 by a predesigned template.

Data quality was assured by taking a 10% sample of study subjects and rechecking the correctness and consistency of the data. Incorrect and inconsistent data was rechecked with the chart and corrected accordingly.

Data Analysis

Data cleaning and analysis was done using EPI Info and SPSS version 15. Data as first analyzed using exploratory and descriptive statistics, followed by bivariate analysis to see the crude effects using logistic regression and cox regression. Data was analyzed to see the prevalence of loss to FUP, the peak time of LTFU. Multivariate analysis was performed to identify factors independently associated with LTFU after checking for significant correlations to avoid multicollinearity. STATA 10 is used to perform selected analysis and for graphing.

Operational definitions

LTFU: A patient who has not reported to the clinic for one month from last date of appointment

Transfer out: A patient for whom referral paper is written to continue care in another health facility and that information is documented on patient chart.

On follow up: A patient who is actively on care and whose last appointment date is yet to come.

Died: A patient who died after starting ART and that information is documented on patient chart.

II. Qualitative Part

Study design: a qualitative approach which tried to describe the perspectives of those who were /are lost to follow up. Patients classified as LTFU were contacted by telephone and in person by members of clinical care giver team and invited to participate in in-depth interview. Those willing and traceable were interviewed by the investigator using an interview guide. Selection is purposive with variation. At least two patients were interviewed from each sex (male and female), disclosure status and religion. Eight Interviews were made until point of saturation or redundancy. Moreover key informants like activists of PLH, Expert patients, Home based care providers and health care providers were also interviewed. Qualitative data was transcribed, translated to English and coded using Open Code software. The thematic approach was used for the analysis with the help of Open Code.

Ethical considerations

Part A of the study did not involve contact with human subject, all the information was collected from the chart initially collected for routine care purposes. There was no direct benefit to the study participants but the output from the study will be used to reduce LTFU from ART by identifying the risk factors of LTFU and improving care. The risk associated with Part A of this study is loss of confidentiality of HIV status and other clinical and demographic information. Appropriate measures to protect data security and confidentiality were taken. Data was

abstracted from charts to data collection form by trained staffs who are already involved in the patient's care. All abstracted data was handed to the investigator in hand. Abstracted data does not contain patient identifying information like name, exact address (House number). All computers, flash disks and other digital information devices that contain data are password protected and stored in lockable cabinets or offices accessible only to the investigator.

Informed consent: Since Part A of the study involves review of charts (data collected for routine care purposes), doesn't involve contact with human subject, as it is practically impossible to access all those who are LTFU and the output of the study will be useful to improve care for participating individuals and beyond, I asked waiver of informed consent for this part and that was approved by the reviewing IRB.

Part B Ethical considerations: LTFU patients were contacted by telephone by a member of the care giver team. This is in fact part of care in the national ART program (tracking lost patients). Those willing were invited to participate in in-depth interview and informed consent was obtained. The interview was conducted in a confidential place in the Hospital. Participants were reimbursed for transportation. The study was ethically cleared by UOG IRB and relevant bodies.

Dissemination and Utilization of results

The results and recommendations will be forwarded to the Hospitals, RHB/RHAPCO, FMoH/FHAPCO. Moreover local and international stake holders including PLWH associations, Community based organizations, organizations giving home based care, US government Universities giving technical assistance to the national ART program, CDC, MSH, USAID, WHO etc will also be given the final report. If resources allow, I will try to organize a workshop

to disseminate and discuss on the findings and recommendations with these stakeholders, perhaps together with other colleagues. All effort will be made to publish the final output in a peer reviewed journal.

Results

The participants are 55.4 % female, and mean age at enrolment was 34.4 years (SD=9.2). Men were significantly older at enrolment than females, (mean 35.9 Vs 33.3, mean diff= 2.60 years, p=.000). Three hundred twenty patients are never married (29.6 %) while 333 are married (30.8 %), 147 (13.6 %) widowed. Most patients (377) have primary education, while only 54 (5%) have tertiary education. Orthodox is the religion of majority representing 841 (78.1%), and 58.7% have child(ren). The mean number of children a patient has is 2.26, but most, 129 (37.8%) have one child. Majority of the patients, 727 (70.7%) live in Addis Ketema sub city, which is the catchment area for the Hospital. Missionary of Charity is the next commonest address provided by patients. Almost all patients provided care giver or contact person address and information.

The average weight of participants was 50.6 kg (SD=10), Male are heavier than females (mean diff=7.36, 54.7 Vs 47.3 p=.000), The median height is 162.2 cm (IQR:156, 169). The data for Height and Weight is not normally distributed as expected. Typically there is clustering of Weight measurements at multiples of 5.

Most patients 655 (60.7%) are in the functional status category of Ambulatory while 119 (11 %) are bed ridden. WHO clinical stage 3 is where 8134 (75.4%) of patients fall while only 124(11.5 %) are classified as stage 4. The average CD4 count at start of ART is 113 (SD: 79.4) , The median CD4 count at start of ART is 102 (IQR:48, 166). Majority of patients, 662 (60.8 %) were started with the regimen d4T-3TC-NVP, while only 59 (5.4%) were initiated on AZT-3TC-EFV.

The year of 1998 has the highest number of patients initiating treatment, while 2000 E.C has fewest. Side effects of treatment was documented in the chart of only 49 (6.3%) of patients.

Table 1: sociodemographic characteristics of patients started ART in St Peters Hospital from Megabit 1998-HIdar 2000 E.C

Variable	Deaths, n (%)	Transfer outs, n (%)	LTFU, n (%)	On treatment n (%)	Total n (%)
Sex					
Male	83(17.7)	55 (11.7)	157(33.4)	175 (37.2)	470(44.6)
Female	79(13.5)	42 (7.1)	201(34.4)	262(44.8)	584(55.4)
Age					
15–24	12(11.4)	5(4.7)	49(46.6)	39(37.1)	105(9.8)
25–34	70(14.7)	45(9.4)	172(36.2)	188(39.5)	475(44.3)
>=35	83(16.8)	49(9.9)	144(29.2)	217(44.0)	493(45.9)
Marital status					
Never married	48(15.0)	28(8.75)	119(37.1)	125(39.0)	320(29.6)
Married	48(14.4)	25(7.5)	106(31.8)	154(46.2)	333(30.8)
Separated	20(17.4)	12(10.4)	37(32.1)	46(40)	115(10.6)
Divorced	25 (15.2)	24(14.5)	60(36.3)	56(33.9)	165(15.3)
Widowed	23(15.6)	12(8.1)	44(29.9)	68(46.2)	147(13.6)
Educational statues					
No education	32(10.1)	41(12.8)	135(42.4)	110(34.5)	318(29.5)
Primary	64(17.0)	30(7.9)	124(32.8)	159(42.1)	377(35.0)
Secondary	62(18.9)	21(6.4)	91(27.7)	154(46.9)	328(30.4)
Tertiary	8(14.8)	7(12.9)	15(27.7)	24(44.4)	54(5.0)
Religion					
Muslim	31(19.1)	7(4.3)	45(27.7)	79(48.7)	162(15.0)
Orthodox	123(14.6)	79(9.3)	303(36.0)	336(39.9)	841(78.1)
Protestant	12(16.2)	12(16.2)	16(21.6)	34(45.9)	74(6.9)
Children at home					
Yes	90(14.8)	52(8.5)	190(31.2)	276(45.3)	608(58.7)
No	71(16.6)	38(8.8)	160(37.3)	159(37.1)	428(41.3)
Care giver information provided					
Yes	155(16.2)	81(8.4)	303(31.7)	416(43.5)	955(90.4)
No	9(8.9)	16(15.8)	49(48.5)	27(26.7)	101(9.6)

Table 2: Clinical characteristics of patients started ART in St Peters Hospital from Megabit 1998-HIdar 2000 E.C at start of ART, AA, June 2009

	Deaths	Transfer outs	LTFU	On treatment	Total
Height (Mean)	162.4(25.1)	164.4(25.3)	162.1(25.0	159.4(24.5	
Weight (Mean)	47.7(23.7)	51.7(25.7)	49.4(24.5)	52.3(26.0)	50.6
BMI(Mean)	18.2(23.8)	19.2(25.1)	19.0(24.8)	20.0(26.1)	76.4
<16	22(21.2)	9(8.6)	41(39.4)	32(30.7)	104(11.7)
16-16.99	27(29.3)	5(5.4)	28(30.4)	32(34.7)	92 (10.3)
17-18.5	27(14.8)	22(12.0)	58(31.8)	75(41.2)	182 (20.4)
>18.5	51(9.9)	47(9.1)	154(29.9)	262(50.9)	514 (57.6)
Functional status					
Working	16(5.3)	20(6.5)	83(27.3)	185(60.8)	304(28.2)
Ambulatory	112(17.1)	70(10.6)	235(35.8)	238(36.3)	655(60.7)
Bed ridden	38 (31.9)	8(6.7)	48(40.3)	25(21.0)	119(11.0)
WHO stage					
1	0(0)	2(16.6)	1(8.3)	9(75)	12(1.1)
2	5(3.9)	5(3.8)	38(29.4)	81(62.7)	129(12.0)
3	142(17.5)	82(10.0)	282(34.6)	307(37.7)	813(75.4)
4	19(15.3)	9(7.2)	45(36.2)	51(41.1)	124(11.5)
CD4 count (Mean)	74(17.0)	126(28.8)	108(24.7)	128(29.3)	113
<50	76(26.0)	24(8.2)	109(37.3)	83(28.4)	292(26.8)
50-199	81(12.5)	59(9.1)	214(33.1)	292(45.2)	646(59.3)
200-350	9(6.5)	17(12.3)	41(29.7)	71(51.4)	138(12.7)
>350	1(8.3)	1(8.3)	6(50)	4(33.3)	12(1.1)
CD4 count (median)	56	124	92.5	126	102
Initial ART regimen					
d4t-3TC-NVP	124(18.7)	60(9.06)	210(31.7)	268(40.4)	662(60.8)
d4t-3TC-EFV	29(13.1)	25(11.2)	94(42.3)	74(33.3)	222(20.4)
AZT-3TC-NVP	9(6.2)	9(6.1)	44(30.1)	84(57.5)	146(13.4)
AZT-3TC-EFV	5(8.5)	7(11.8)	22(37.2)	25(42.3)	59(5.4)
ART started					
1998 E.C	62(17.0)	27(7.3)	121(33.1)	155(42.4)	365(33.5)
1999 E.C	99(15.9)	71(11.3)	214(34.2)	240(38.4)	624(57.3)
2000 E.C	6(6.0)	3(3)	35(35)	56(56)	100(9.2)
Experienced side effect					
Yes	2(4.1)	4(8.1)	11(22.4)	32(65.3)	49(6.3)
No	104(14.2)	53(7.2)	214(29.1)	362(49.3)	733(93.7)

159 patients (18.9%) were working full time at enrolment while 157 (18.7%) not working due to ill heath. Most patients (52.8%) live in one room house. The average number of people per room is 2.65, and median House hold size is 4. 368 patients (33.6%) have not disclosed to any one, brothers /sisters are the most common persons to whom patients disclose, 227(26.2%), and relatives are disclosed of HIV status in 103 (11.9%) patients.

Understanding of HIV disease is rated as ++ or +++ in 30% of patients, understanding of HIV transmission was adequate (++ or +++) in 60.7 % patients. Understanding about OIs and ART medication adherence was very low with only 27 % and 22.6% patients rated as ++ or +++ respectively.

Information on regular sexual partner was obtained only in 588 (53.7%) of patients and of these, 47.2 % are documented to have regular sexual partners. Information on casual partners and their numbers in the last 3 months is also rare, found only in 216 (19.7%) of patients. Of these 67.6 % have at least one casual partner in the last 3 months and 37 (17.1 %) have more than 3 casual partners in the 3 months before enrolment. Substance use is not common, with 246(37.3%) using alcohol,153(23.2%) use tobacco, 229(34.7%)use soft drugs like khat and shisha and only 31(4.7%)use hard drugs like cocaine . 319 (29.1%) patients have at least one documented adherence concern with forgetting to take medications being the commonest one being reported in 178 (16.6%) of patients.

Table 3: Social and behavioral characteristics of patients started ART in St Peters Hospital from Megabit 1998-HIdar 2000 E.C at start of ART, AA, June 2009

	Deaths n (%)	Transfer outs n (%)	LTFU n (%)	On treatment n (%)	Total
Current employment					
working full time	13(8.2)	14(8.8)	37(23.2)	95(59.7)	159(18.9)
Working part time	1(5.9)	0(0)	6(35.2)	10(58.8)	17(2.0)
Not working/studying due to ill health	34(21.7)	10(6.3)	58(36.9)	55(35.0)	157(18.7)
Unemployed	85(16.8)	55(10.8)	177(34.9)	190(37.4)	507(60.3)
Number of people peer room(median)	2	1.7	2	2	2
Community support /HIV support group					
yes	11(8.5)	19(14.7)	54(41.8)	45(34.8)	129(15.8)
No	122(17.8)	57(8.2)	217(31.5)	291(42.3)	687(84.2)
Disclosure (does anyone else know about your HIV status)					
No					368(33.6)
Wife/Husband	27(14.5)	13(6.9)	53(28.4)	93(50)	186(21.4)
Own child(ren)	15(17.0)	1(1.1)	30(34.09)	42(47.7)	88(10.1)
Parent/s	34(21.3)	8(5)	56(35)	62(38.7)	160(18.4)
Brother(s)/Sister(s)	50(22.0)	21(9.2)	64(28.1)	92(40.5)	227(26.2)
Relatives	11(10.7)	10(9.7)	35(33.9)	47(45.6)	103(11.9)
Friends	13(12.6)	14(13.5)	33(32.0)	43(41.7)	103(11.9)
Understanding of HIV disease					
NA	5(13.9)	4(11.1)	19(52.7)	8(22.2)	36(3.5)
-	49(14.4)	25(7.3)	133(39.1)	133(39.1)	340(33.0)
+	56(16.3)	31(9.0)	121(35.1)	136(39.5)	344(33.4)
++	37(15.1)	25(10.2)	68(27.7)	115(46.9)	245(23.8)
+++	8(12.5)	10(15.6)	16(25)	30(46.8)	64(6.2)
Understanding of HIV transmission					
NA	3(15.8)	1(5.2)	10(52.6)	5(26.3)	19(1.8)
-	33(16.3)	17(8.4)	84(41.5)	68(33.6)	202(19.3)
+	30(15.8)	21(11.0)	73(38.4)	66(34.7)	190(18.1)
++	64(13.7)	39(8.3)	150(32.1)	214(45.8)	467(44.6)
+++	27(16.0)	17(10.0)	43(25.4)	82(48.5)	169(16.1)
Understanding of prophylaxis and treatment of OI					
NA	8(13.3)	4(6.6)	29(48.3)	19(31.6)	60(5.8)
-	92(17.6)	41(7.8)	179(34.2)	210(40.2)	522(50.7)

	Deaths n (%)	Transfer outs n (%)	LTFU n (%)	On treatment n (%)	Total
+	24 (14.2)	17(10.0)	56(33.1)	72(42.6)	169(16.4)
++	24(9.9)	28(11.5)	82(33.7)	109(44.8)	243(23.6)
+++	3(8.6)	3(8.5)	9(25.7)	20(57.1)	35(3.4)
Understanding of ART medication adherence					
NA	10(15.2)	5(7.5)	29(43.9)	22(33.3)	66(6.5)
-	92(17.0)	40(7.3)	192(35.4)	217(40.1)	541(53.4)
+	20(11.4)	20(11.3)	56(31.8)	80(45.4)	176(17.4)
++	24(11.5)	24(11.4)	64(30.6)	97(46.4)	209(20.6)
+++	3(14.3)	2(9.5)	7(33.3)	9(42.8)	21(2.0)
Has regular sexual partner					
yes	45(16.4)	28(10.1)	85(30.9)	117(42.5)	275(47.2)
No	44(14.3)	19(6.1)	91(29.6)	153(49.8)	307(52.7)
casual sexual partner(s)-number of casual partners in last 3 mo					
0	15(21.4)	4(5.7)	10(14.2)	41(58.5)	70(32.7)
1	4(4.7)	7(8.1)	22(25.5)	53(61.6)	86(40.2)
2	7(58.3)	0(0)	3(25)	2(16.6)	12(5.6)
3	2(22.2)	0(0)	3(33.3)	4(44.4)	9(4.2)
>3	3(8.1)	1(2.7)	15(40.5)	18(48.6)	37(17.3)
Substance use					
Smoking tobacco	29(19.0)	15(9.8)	42(27.4)	67(43.7)	153(23.2)
Alcohol use	33(13.4)	26(10.5)	88(35.7)	99(40.2)	246(37.3)
Soft drugs (Khat, shisha) use	35(15.3)	19(8.2)	77(33.6)	98(42.7)	229(34.7)
Hard drugs (cocaine, Iv drugs) use	6(19.4)	3(9.6)	8(25.8)	14(45.1)	31(4.7)
Adherence concerns					
Stigma	17(21.3)	7(8.7)	27(33.7)	29(36.2)	80(22.8)
Afraid of medications	8(13.6)	8(13.5)	21(35.5)	22(37.2)	59(16.8)
Dought that medications will work	5(26.3)	1(5.2)	4(21.0)	9(47.3)	19(5.4)
depressed/anxious	3(21.4)	1(7.1)	4(28.5)	6(42.8)	14(4.0)
Will forget to take medications	25(14.0)	10(5.6)	48(26.9)	95(53.3)	178(50.8)

Disclosure

Disclosure data is available for 1057 of 1095 subjects (96.5%). Brothers/Sisters are the most common persons disclosed to (20.9%), followed by husband/wife (17.1%), parents (14.8%), relatives (9.4%) and friends (9.4%). Selecting only those who are married at enrollment, only 50.9% have disclosed their status to their spouse at enrollment. 33.6% of patients have not disclosed to any one at enrollment, 55.7% have told to one person and 10.7 % told to two or more persons.

Table 4: frequency distribution of Number of individuals disclosed to

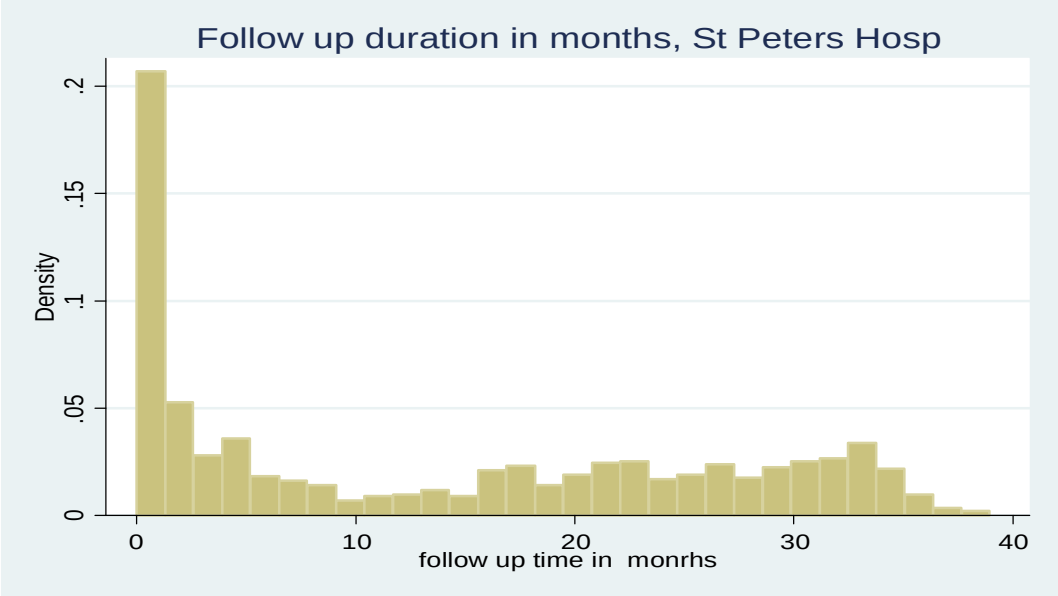
No of individuals disclosed to	Frequency	Percent	Cumulative Percent
0	368	33.6	33.6
1	610	55.7	89.3
2	92	8.4	97.7
3	23	2.1	99.8
4	1	.1	99.9
5	1	.1	100.0
Total	1095	100.0	

On x2 statistics and binary logistic regression, none of the disclosure variables alone have significant correlation with loss to follow up, but disclosing to any one and the number of persons disclosed to are protective of loss to follow up.

Longitudinal data and survival analysis

1094 patients were enrolled and followed up contributing to a total person time of 1234.36 person years (15,018.1 person months). The mean follow up time (Last actual visit date - ART start date) is 13.7277 months (SD:12.559, CI: 12.98, 14.47), and it ranges between 0.00 and 38.97 months. The median months of follow up is 11.27 (IQR: 1.033, 25.72). Kolmogrov-Snirnov test of normality, the histogram, normal q-q and box-whisker plots all show significant deviation of the follow up duration distribution form the normal distribution with left skewedness (p=.000).

Fig 1: Histogram distribution of follow up time before an event or censorship, June 2009, St Peters Hosp, AA

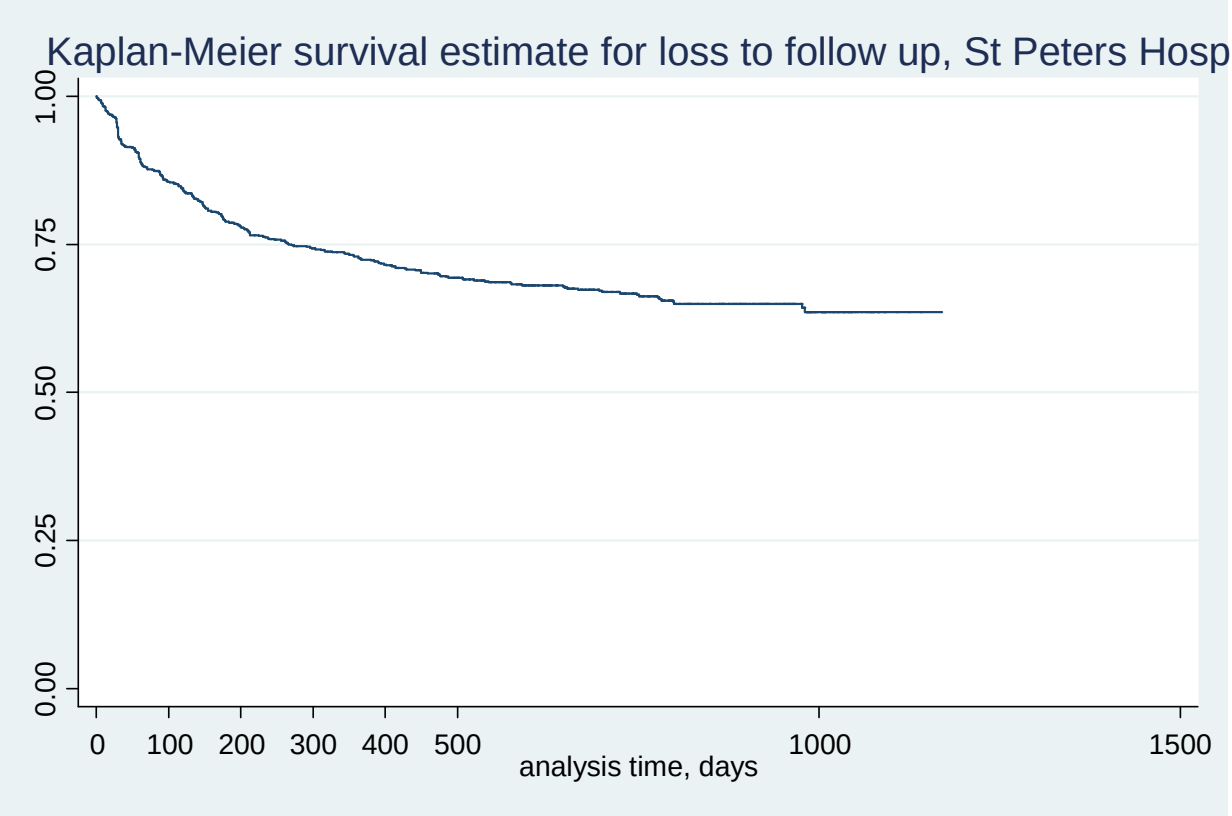


The outcome is recoded into a binary variable, lost to follow up and not lost to follow up and survival analysis performed. The mean survival time is 2.077 years (1.985, 2.168). kaplan meir statistics is used to plot survival curve.

Cumulative Incidence

Of the 1234.36 person years of follow up, 370 LTFUs occurred, giving a cumulative incidence of 299.8 per 1000 person years, or an incidence density of 29.98% per year, CI: 269, 330.

Fig 2: Kaplan meir survival curve for the entire study population, June 2009, St Peters Hosp, AA



Follow up pattern of lost patients

For patients lost to follow up, the mean time of follow up is 139.84 days (SD: 192, CI: 120, 159.5), and the median is 59 days, (IQR: .00, 193), it ranges between 0 and 981 days. 25.7% of lost patients have a follow up time of zero, i.e., have not come after the ART start date. The distribution is highly skewed to the left with a skewness of 1.905. The incidence of loss to follow up is highest in the first two months after start of ART, then declines and is relatively stable from 3rd to 6th months. The rate then drops significantly after 6 months to continue further decline after 12 months.

Cox regression is used to test between an independent variable and incidence of loss to follow up. All variables were tested using this model and among the variables which showed Significance on binary cox regression, age, higher educational status, religion (being protestant), having children, providing care giver information, bigger weight or BMI, working or ambulatory functional status, WHO stage 1, higher baseline CD4, employment, disclosure to any one, disclosure to spouse, disclosure to many people, understanding about HIV disease, understanding about HIV transmission, understanding about OIs, having concern about forgetting to take medications, having any concern about adherence and the number of identified concerns about adherence were protective. For each one year increase in age, the force of LTFU decreases by 2% while having children at home decreases it by 23%. Those who have not disclosed have a 40% more hazard of being lost compared to disclosed ones. More over having casual sexual partner in the last 3 months and having community support were risk factors for loss to follow up. These variables were further tested with multiple cox regression to control for confounders after checking for collinearity.

Table 5: statistical tests (events, B, P, HR and CI) for demographic variables using cox regression in ART patient cohorts of St Peters Hosp

Variable						**CI for HR**	
	Event	**Censored**	**B**	**P**	**HR**	Lower	upper
Age	364 (33.2%)	708 (64.7%)	-0.018	0.003	0.982	0.971	0.994
Sex	357 (32.6%)	696 (63.6)	.008	0.943	1.008	0.818	1.242
Marital Status	365 (33.3%)	714 (65.2%		0.266			
Educational statues	364 (33,2%)	712 (65.0%)		0.001			
No education			0.506	0.063	1.658	0.973	2.828
Primary			0.184	0.501	1.202	0.703	2.055
Secondary			-0.028	0.92	0.973	0.563	1.679
Tertiary					1		
Children at home	349 (31.9%)	686 (62.6%)					
Yes			-0.258	0.017	0.773	0.626	0.954
No					1		
Numb of Children	113 (10.3%)	230 (21%)	0.003	0.967	1.003	0.885	1.136
Care giver information provided	351 (32.1%)	704 (64.3%)					
Yes			-0.593	0	0.553	0.408	0.748
No					1		

Table 6: statistical tests (events, B, p, HR and CI) for clinical variables using cox regression in ART patient cohorts of St Peters Hosp

Variable						**CI for HR**	
	Event	**censored**	**B**	**P**	**HR**	Lower	upper
Height	284 (25.9%)	617 (56.3%)	-0.001	0.884	0.999	0.986	1.012
Weight	353 (32.2%)	693 (63.3%)	-0.025	0	0.976	0.965	0.987
BMI	280 (25.6%)	611 (55.8%)	-0.072	0	0.93	0.894	0.968
Functional status	365 (33.3%)	712 (65%)		0			
Working			-0.986	0	0.373	0.261	0.534
Ambulatory			-0.446	0.005	0.64	0.469	0.874
Bed ridden					1		
WHO stage	365 (33.3%)	712 (65%)		0.038			
1			-1.719	0.089	0.179	0.025	1.301
2			-0.414	0.062	0.661	0.428	1.021
3			-0.006	0.968	0.994	0.723	1.365
4					1		
CD4 count	369 (33.7%)	718 (65.6%)	-0.002	0.001	0.998	0.996	0.999
Initial ART regimen	369 (33.7%)	719 (65.7%)		0.011			
d4t-3TC-NVP			-0.106	0.636	0.899	0.58	1.396
d4t-3TC-EFV			0.213	0.368	1.238	0.778	1.97
AZT-3TC-NVP			-0.355	0.174	0.701	0.42	1.17
AZT-3TC-EFV					1		
ART started	369 (33.7%)	719 (65.7%)		0.466			
1998 E.C			-0.061	0.751	0.94	0.644	1.373
1999 E.c			0.079	0.665	1.082	0.756	1.549
2000 E.c					1		
Experienced side effect	224 (20.5%)	557 (50.9%)					
Yes			-0.471	0.127	0.624	0.34	1.144
No					1		

Table 7: statistical tests (events, B, p, HR and CI) for social and behavior variables using cox regression in ART patient cohorts of St Peters Hosp

Variable						**CI for HR**	
	Event	**censored**	**B**	**P**	**HR**	lower	upper
Current employment	277 (25.3%)	562 (51.3%)		0.004			
working full time			0.599	0.001	0.549	0.385	0.783
Working part time			0.147	0.723	0.863	0.383	1.948
Not working/studying due to ill health			0.13	0.393	1.139	0.845	1.535
Unemployed					1		
Community support /HIV support group	270 (24.7%)	545 (49.8%)	0.384	0.012	1.468	1.089	1.979
Disclosure (does anyone else know about your HIV status)							
Disclosure status(No/Yes)	369 (33.7%)	719 (65.7%)	0.331	0.002	1.393	1.131	1.715
To Wife/Husband	352 (32.1%)	698 (63.7%)	-0.286	0.055	.751	0.561	1.006
To Own child(ren)	352 (32.1%)	698 (63.7%)	-0.025	0.895	0.975	0.671	1.418
Parent/s	352 (32.1%)	698 (63.7%)	0.108	0.457	1.114	0.838	1.483
Brother(s)/Sister(s)	352 (32.1%)	698 (63.7%)	-0.195	0.161	0.823	0.626	1.081
Relatives	352 (32.1%)	698 (63.7%)	-0.072	0.687	0.931	0.656	1.32
Friends	352 (32.1%)	698 (63.7%)	-0.019	0.917	0.981	0.686	1.404
Number of Disclosures	369 (33.7%)	719 (65.7%)	-0.172	0.028	0.842	0.722	0.982
Understanding of HIV disease	356 (32.5%)	672 (61.4%)					
NA			1.233	0	3.432	1.763	6.681
-			0.598	0.024	1.818	1.082	3.054
+			0.487	0.067	1.627	0.966	2.741
++			0.143	0.608	1.153	0.668	1.99
+++					1		

Variable						CI for HR	
	Event	censored	B	P	HR	lower	upper
Understanding of HIV transmission	359 (32.8%)	687 (62.7%)					
NA			1.209	0.001	3.35	1.679	6.684
-			0.736	0	2.088	1.441	3.026
+			0.577	0.003	1.781	1.218	2.605
++			0.313	0.073	1.368	0.971	1.927
+++					1		
Has regular sexual partner	176 (16.1%)	406 (37.1%)					
Yes			0.086	0.569	1.09	0.81	1.466
Has Casual partner	53 (4.8%)	161 (14.7%)					
Yes			0.241	0.005	1.272	1.074	1.507
Substance use							
Smoking tobaco	347 (31.7%)	669 (61.1%	-0.266	0.106	0.766	0.555	1.058
Alcohol use	352 (32.1%)	673 (61.5%	0.016	0.895	1.016	0.798	1.294
Soft drugs (Khat, shisha) use	352 (32.1%)	672 (61.4%)	-0.059	0.649	0.943	0.732	1.214
Any substance use	369 (33.7%)	719 (65.7%)	-0.036	0.482	0.965	0.874	1.066
Adherence concerns							
Stigma	361 (33%)	702 (64.1%)	0.068	0.735	1.07	0.723	1.584
Afraid of medications	361 (33%)	703 (64.2%)	0.018	0.937	1.018	0.655	1.582
Dought that medications will work	360 (32.9%)	703 (64.2%)	-0.576	0.252	0.562	0.21	1.507
depressed/anxious	361 (33%)	703 (64.2%)	-0.124	0.805	0.883	0.33	2.367
Will forget to take medications	361 (33%)	703 (64.2%)	-0.469	0.003	0.626	0.461	0.848
Number of concerns	369 (33.7%)	719 (65.7%)	-0.239	0.022	0.788	0.642	0.967
Any concern (no vs yes)	369 (33.7%)	719 (65.7%)	0.332	0.006	1.394	1.101	1.767

Fig 3: survival estimate curve by the concern “will forget to take medications, June 2009, St Peters Hosp, AA

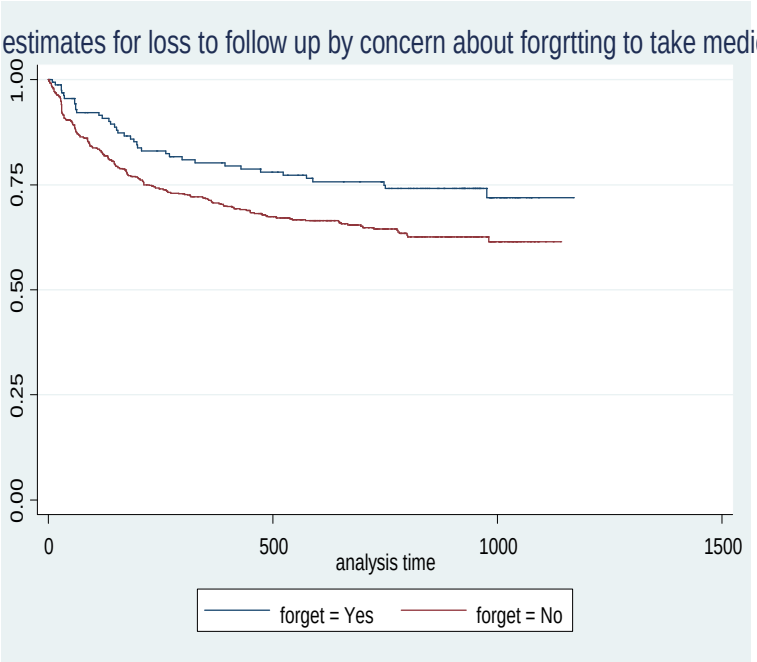


Fig 4: survival estimate curve by any concern about adherence June 2009, St Peters Hosp, AA

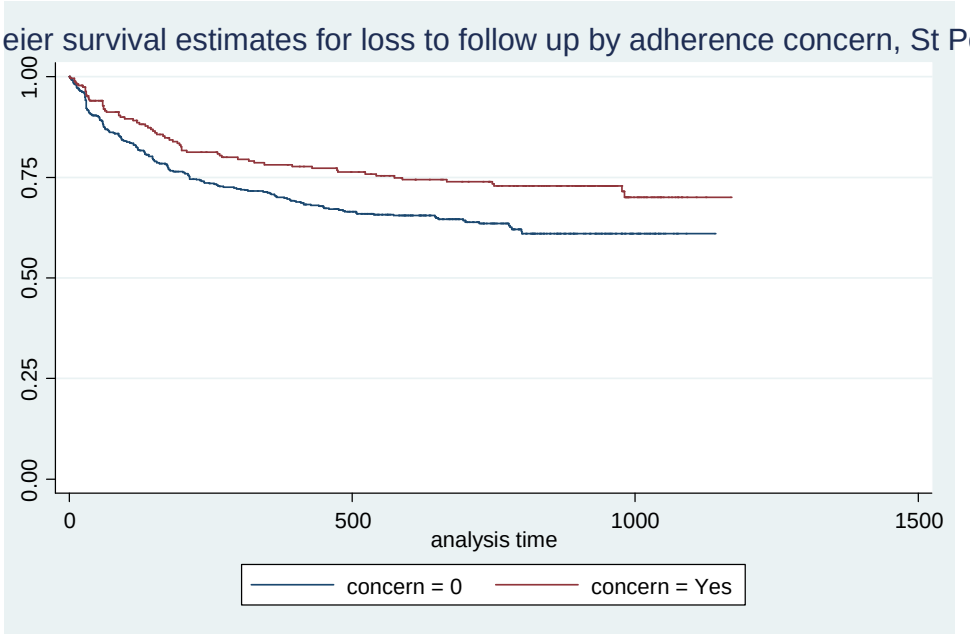
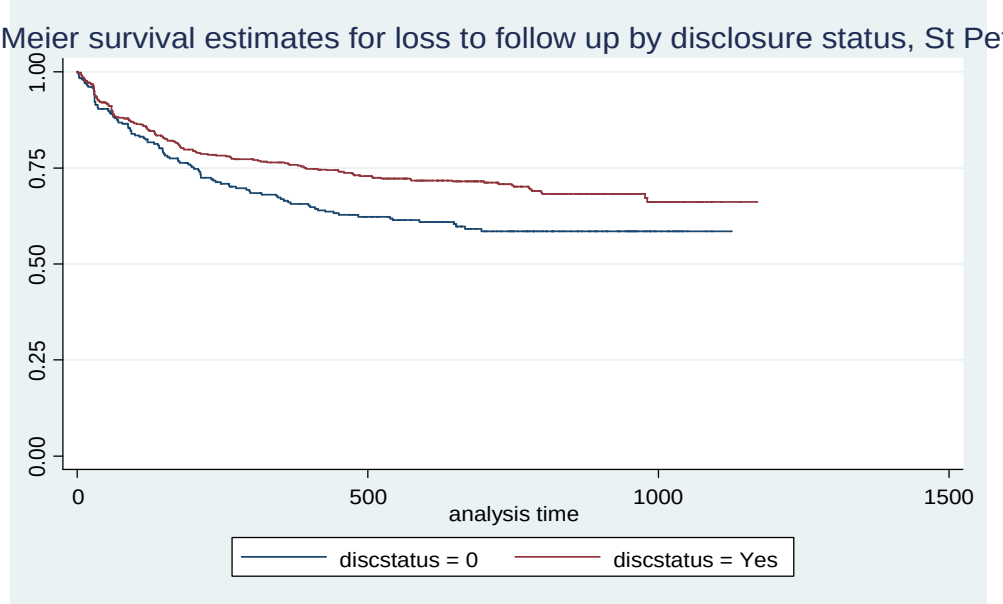


Fig 5: survival estimate curve by disclosure status, June 2009, St Peters Hosp, AA



Multivariate analysis

All significant variables were tested for collinearity by pearson correlation test and those without significant correlation (r2<.5) were included step by step in multiple cox regression to test for independent predictors of loss to follow up and adjust for possible confounders. After adjustment for all variables predictors which remained significant are age (p=.014, HR=.98), functional status (p=.044, HR=.54), baseline CD4 count (p=.037, HR=.998) and Understanding of HIV disease (p=.018, HR=3.325). Being in a working functional status decreases the hazard of LTFU almost by half when compared to bed ridden patients.

Table 8: Multiple cox regression for selected variables in the ART cohorts of St Peters Hosp

	B	SE	P	HR	95.0% CI for HR	
					Lower	Upper
Age	-.019	.008	.014	.981	.966	.996
Education status			.232			
No education	-.138	.322	.669	.871	.463	1.638
Primary	-.399	.315	.205	.671	.362	1.243
Secondary	-.361	.313	.249	.697	.378	1.287
Tertiary				1		
Religion			.105			
Muslim	.426	.364	.242	1.531	.750	3.124
Orthodox	.626	.332	.060	1.870	.975	3.587
Protestant				1		
Children at home	-.058	.138	.674	.944	.720	1.236
Care giver information	-.281	.203	.167	.755	.507	1.124
Weight	-.005	.008	.548	.995	.981	1.010
Functional status			.044			
Working	-.608	.244	.013	.544	.337	.878
Ambulatory	-.347	.203	.087	.707	.475	1.051
Bed ridden				1		
Who stage			.326			
One	-1.210	1.034	.242	.298	.039	2.261
Two	.250	.288	.386	1.283	.730	2.256
Three	.240	.202	.235	1.271	.856	1.886
Four						
cd4atstart	-.002	.001	.037	.998	.996	1.000
Initial regimen			.314			
1a	-.072	.278	.795	.930	.539	1.605
1b	.169	.292	.562	1.184	.669	2.097
1c	-.233	.325	.472	.792	.419	1.497
1d				1		
Understanding HIV disease			.08			
NA	1.201	.509	.018	3.325	1.227	9.009
-	.239	.349	.493	1.270	.641	2.517
+	.248	.344	.470	1.282	.653	2.515
++	.003	.346	.994	1.003	.509	1.974
+++				1		

	B	SE	P	HR	95.0% CI for HR Lower	Upper
Understand HIV transmission			.349			
NA	-.142	.597	.811	.867	.269	2.794
-	.468	.266	.079	1.596	.948	2.689
+	.425	.254	.094	1.529	.929	2.516
++	.300	.226	.184	1.350	.867	2.102
+++						
Disclosure						
Wife or husband	.126	.177	.476	1.135	.802	1.606
Number of Disclosures	.130	.149	.381	1.139	.851	1.524
Disclosure Status	.264	.221	.233	1.302	.844	2.009
Concern						
forgetfulness	-.215	.234	.359	.806	.509	1.277
Any Concern	.217	.187	.245	1.243	.861	1.793

Qualitative data

Reaction to HIV positive status

There are many types of reactions described by interview participants to knowledge of HIV positive status and uncertain future. One patient said "my mind has accepted it soon. As soon as I started…." Another patient described it as "I didn't have any fear, I told you, after I accepted it, I didn't even think that I am sick" A bold description on the other extreme.

But the commonest responses are shock, denial, anger and the "WHY" question, described by some as "I don't know, what can you do once it happened, first you are shocked, your inside will be shocked but..." or as "I was shocked; I cried too much because … Why on me, without doing anything, had I done something or…" or as "There is denial, I didn't believe when I tested initially,… When I heard I almost fell down, but he [the doctor] supported me, have me sat down…" or "It was shocking ("dub eda"), and unexpected…. When he [the doctor] told me I

just fall down…I think why I got sick so soon is lack of acceptance ("meregagat"), and [thinking] 'how this could happen?…' ". Some even appear to express their anger outwards. This participant was tested long ago, 10 years when the level of stigma was high and treatment not as readily avalable. She describes her reaction as "I used to be afraid of everything. I was shocked and I hated people. I used to like people before [that] but right after the time I heard about [my status], I started to hate them. Being alone makes me happy ….I started connecting things that happened to me with people, saying why did I get exposed to this?...I used to hate doctors when I see them….they are the ones who told me [lough]…" It seems those who believe they are passive, have no active role in acquisition of the infection find it more difficult to accept than those who believe having some active role in the infection.

ARVs

Majority , almost all have the experience and testify the improvements they have enjoyed after starting ART. "Yes, I was very sick. But When I started the medications, I got up and walked in the 12th day. I am very healthy since then." The HBC worker said "Yes, Most of them say we got change; we were bed ridden now we are working, moving around".

But deciding to start the medications and coming to the health facility for the first time is not a simple issue for most, although it seems an instantaneous decision without an option, and eager to get improvement, for some. This is described as "I had no concerns or fears Since I was so eager to get cured, my mind has accepted it soon….Yes, they used to say that [myths about the medication] but I was not afraid. Since I was so eager to get cured, I convinced myself that I will be cured, so nothing" Another patient was describing the time around start of follow up and ART

"I was so eager to start the ARVs, to start sooner, so that I see the difference, other wise I didn't [have the fear]…"

On the other hand fear and emotional instability, struggling with oneself is common before start of ART. "[I was] too emotionally unprepared to start the medication… Yes I did [disappear], because of all these conditions I disappeared from here [hospital] for 15 days. After 15 days, I came in ..." The other patient said "then it [CD4] was too low. So you have to start the medication he [the doctor] said, I was not happy about the medication, I didn't want to start…Let alone the medication, the testing of CD4 I didn't want …" Those with such struggle and concern to start ART have discontinued for reasons under their control e.g: going to Holy water but those who appeared eager to start the medications discontinued for reasons beyond their control E.g: going to regions to attend a funeral of a mother, "forbidden" to take the medications with holy water, high cost of medications when the free treatment had not started.

Concerns before starting ART

Cost of the medication could have been a significant concern and a problem without solution had it not been free. Those who started ART long ago (before the free treatment) had to go through this. One patient described it as "I started the medication with 1500 birr a month, after I took

it for about 3 months they [my family] complained that they couldn't afford it. During that time I was so eager to get cured, but since I couldn't do anything I went to a holy water….Yes that[cost] was my worry"

Some patients have minimal fear or concern (especially those describing themselves as accepting the status, eager to get "cured" or improved) while others have significant concerns. "There was nothing [fear], I take it on time, I take on time now I take on time when I started.

But majority of patients especially those who have not disclosed and have not yet accepted their status express a lot of concerns. The stringent adherence requirement is also another source of concern for many. "Yes, What time should I take, I might be seen by the kids or her [my wife], this is worrying and choosing the time …"

Or " I won't take it appropriately, I can't keep the time, if not taken properly, or you delay a minute the virus will grow, how long will I do this? Without missing a minute? Other medications we take it as we like, how can this be taken without missing a minute? So for this reason, beqa.,,"

Concern about side effect of the medication

There is a mixed feeling among majority of PLH about to start ART on the benefit of medications and some horrible side effects they have heard or seen. "I had no concerns or fears since I was so eager to get cured, my mind has accepted it soon. As soon as I started the medications, He has already told me, something might appear in your body….I said OK and I accepted it… the medication did not hurt me"

Side effect of medications is a concern for almost all, but the magnitude and the way it is expressed differs. Those who got good education and counselling and those accepting their status and "eager" to get improvement seem to be more likely to accept and tolerate the side effects

better. One of such patient said “the medications, He has already told me, something might appear in your body, If you do what is recommended you will pass that time, You will have rash, like acne in your body, have nauseas or vomiting. As he told me this I said OK and accepted it. I had rash eruption… ‘beqa’ “ . The home based care worker talking about her conversation with a patient about to start ART “No, But he was a little concerned when he saw another man, he saw him[another man] with rash, I told him that is the nature of the medication, and relieved. Will this happen to me he asked, No, It won’t, it is not similar in all persons…Yes He is concerned, but I am supporting him. “

Many rumours or sayings about the medications in the community are also sources of concern. “The other thing was some people say when you take medications, the face swells, darkens such things, when some people have swollen and dark faces, they say He has HIV… earlier when a person face swells and darkens it is said it is the medications, it is because he is taking the medications… while taking the medication, their faces darkened and died,”

Anxiety is expressed as a concern only by one patient. Others although did not mention the term, they repeatedly talked about alternative similar words like worry, concern, .

The nurse interviewed also noticed similar concerns worded by patients. “…The medicine does this, does that so it is better if you don’t start the medicine… Most are afraid of the stigma, some people are afraid of the side effect of the medicine and the other thing is fasting. ..Most of them for example, they might not know about the side effect but they hear rumours.”

Stigma and Disclosure of HIV status

This probably is the biggest concern for almost all patients. Majority of the patients prefer not to disclose their HIV status to family members, friends, relatives, neighbors or employers at least for some time, for fear they would be stigmatized. "…without disclosing. Had she knew, in fact she [the employer] would have Stigmatized me…" and most, if not all, have experienced or at least perceived an action as stigmatizing, mainly from the above mentioned social groups. "But as if I have done nothing, because of this disease, I was made not to work, this disappoints me so much. I feel …"

"That girl, daughter of somebody, when they found out, they kicked her out of the house, there are some rumours like that…" The same fear is noticed by HBC worker "No, the fear the stigma, if some body finds out, if the family finds out stigmatize, so because of this they say we don't come… fear of knowledge of their status…"

Reveal of HIV positive status is also a headache for many. The expert patient working in ART clinic expresses this as "They don't want to be seen, or see each other or another person [in ART clinic]. Many run and get in to our office; they say some body saw me. She should not see me. That Is it. There is hiding like that.

When a patient is talking how he would take the medications in the presence of a friend he said "If there is a friend you will say yah it [the medication] is nothing blah blah…" Another patient expressing the difficulty to keep adherence and keeping his status hidden from family said "You can't hide it [the medication] easily, you can't take it hiding form you family… if I discuss it, It

is so worrying, what time should I take, when nobody can see me, the kids, others, what time is free? 6:00 AM? 6:00PM? 12:00AM? 12:00PM? Choosing the time is so worrying, that hurt me"

All agree that the problem of stigma is decreasing; especially those who knew their status long time ago have long experience. "I was afraid of people knowing I had it [HIV]. What would they might tell others…" But in almost all, after they have disclosed to family or friends the response is usually supportive. "She takes a good care of me, she also had counselling here, so she takes care of me" said the patient who had tremendous worries to disclose to wife, after disclosure.

"They said no problem and her son too, and others, all her children are educated, and good, they supported me and gave me morale ("Ayzosh") and there is also my neighbour,… Now, she[my doughter] doesn't want me to miss a minute on the medication. She tells me she reminds me." is the experience of another patient after disclosure, even children when they know the status are very supportive.

The Future, Uncertainty, Sickness and Death

Some patients have big problems about accepting status. This sometimes leads to refusal to start treatment and preference to die [passive suicide?]. "I didn't take any, what is the problem if I die and I refused [to start medication]… I thought I was going to die soon, I lost hope. .. , adding the medication too, I feared would kill me". Although some patients say they have accepted it, have positive thinking and always think of "living", the frequent mention of sickness and death in almost every response to all questions tells something. It seems they have to always actively remind themselves that they can live. It is no more a "given" denial. Another patient's words "why, there were three persons who came from Arab country with Herpes zoster and died, from

our family, so 'she might die, she should come soon' said my aunt… Yes, one person has discontinued for three months and he died… he got sick his mother came, took him to countryside, and he died there."

There is no patient who doesn't mention sickness and death in almost every paragraph. "My mother died, and I went to the region. There is nothing, the medication is not available, and people are dying of this…. my mother died and if I die I hurt no one, I am back to soil, But there are many with kids, in our village, OVCs as well…". Even the health workers do recognize this, having to deal with it on daily basis. The interviewed nurse said "when they get lost we say either they are sick or dead."

Children

Concern about children and their future is one way where this uncertainty is expressed for those who have kids. Patient's concerns range from stigma to children and themselves (by the children) to children's development and future if or when the parents die. "… and second the kids are not mature enough to be told. The older ones are not at home, you could have told to one of them, the rest are young, they could get disturbed, and that was my worry. .., this worries me, the kids, we are living in Kebele house, the children are kids, I don't have assets, my worry was they are going to be left without carer ("betignachew"), they might be street children ("bozene") . …that was the main worry… Yes there is too big problem, if it is known that I am HIV positive in the community, the kids will be stigmatized ("metekuakemia"). His father is such, his father when they play or pass by, this is a huge burden to their mind. I had such worries. … the kids, their morale may be hurt, that was my worry…. What if someone know when I take medications,

what will happen to my kids, what will they say, when they grow up and know? what will they feel? What will they feel if they even suspect this? " Another patient does also have similar worries. "Yes, I am so much concerned for my daughter, I wanted her to be tested and know her status, she is negative, and she is now 12 years old. She is 6 grader. My fear was, Initially I didn't want her to know but she knew, by speculation…. I thought if she knew, she will be shocked, disappointed or even she may run away from me. She was living with me and I was afraid she might run away. Let alone her, there are my brothers children, they know too, and take a very good care of me, they visit me, they visit me they are students of 5th and 6th grade, her peers, but the kids are very good, have good understanding. "

Understanding about ART and adherence and OI

Like a rule, all patients said their understanding of adherence and the medications was poor when they were to start ART. It is only after they are given education and counselling that their knowledge improved.

The HBC worker said "They don't have much knowledge, we give them basic education…and they have improvement in knowledge." One patient said "I don't have any knowledge, after I get tested and knew my status …I didn't know anything about the medication … No I didn't, I learnt [about adherence] from the doctors .. That too [about OIs] I learnt from the doctors" Another patient referring to the ART said "No I didn't [know]. I thought it is taken once or twice, I also thought it was an injection". But the perspective of the nurse about baseline knowledge of patients is a little different: "It is difficult to say all of them don't have knowledge when they first come here, they have the knowledge but when it happened to them they become

new to it, like they know nothing. It becomes a new thing to them with the shock and fear. But all of them tell you what HIV is, what the medicine can do for them. Even people from the country side try to explain certain things very well."

Problems

Many issues are raised as problems for PLH on ART. Poverty and food problem are the most frequently mentioned ones. "They just take the medication to live, there are so many things in everyone's house…" The HBC worker said explaining about one of her clients, when she asked her why she discontinued ART "She said she was angry, because of poverty and deprivation".

Another patient mentioned "Others discontinue, some say they don't have food, poor people there are many who don't have any food, …" and also "nothing to eat, when she has nothing to eat she doesn't want to take the medication. So there are such problems,". Food insecurity is another important reason for discontinuation.

Discontinuation

As mentioned earlier, cost was a significant concern and reason for discontinuation of ART when the treatment was fee based. Now all patients thank the Government and all involved for providing the medication and treatment free of charge. The expert patient describes this as "[when] medication was not available how many of our brothers and sisters are lost? So now we should thank God, one it is free, the treatment is also free, if it were fee based, lot of people could have died, now number f deaths has decreased."

Going to holy water is the reason of all but few of those who discontinued, Other reasons mentioned were sickness or disease and admission to a Hospital, going to the region to attend funerals, bereavement (unforeseen, emergency). Substance use is another mentioned reason for discontinuation especially among the youth. “There is one person I know, I think he discontinued because of addiction”

The expert patient who counsel lost and tracked patients face to face and via telephone says “Many of them say I went to Holy water, most of them and many of them say A relative got sick and I was attending …Yah, as they have the attitude that Holy water and the medication do not go together, they discontinue because of that”. This attitude and crave for cure from this chronic illness is heightened by “rumours” of cure, and emergence of new holy water. The expert patient says “Mostly it is rumours, ‘If you do this you will be this, If you do that you will be that’ such people talks, take people to the grave “gedel”.” The other issue is some religious leaders (few) do not advise taking ART medication with the holy water (especially one holy water site chaplain is mentioned repeatedly). One of the patients interviewed shared his experience “I went to a holy water, Shunkuro, I took the medication with me, my leg was swollen. When I am there they told me I can’t take the medication. How can I come back? I was taken carried by people, It is in the middle of forest. I discontinued for one month”. Patients are motivated by a very appealing promise of cure by holy water as opposed to the very demanding and lifelong treatment of ART. One patient explained this as “When I heard about being healed, I said why don’t I go there and be healed than just taking the medicine [forever]. So, I went and I started [holy water].

Benefit from holy water

One of the interviewees mentioned "…but I got better when I went to holy water, since I had no nagging, I had mental peace. But another patient is less enthusiastic about holy water "God is merciful, but He doesn't give mercy to one and deny the other, We all are sinners and he is going to give us mercy to all of us, just like this in the right way doctors might find the medicine and …"

Problems with discontinuation

Many recognize the problem associated with discontinuation of ART and most have experienced it as well. "I had different disease symptoms… Because they discontinue medication they go back to the illness state…I have seen one girl, She said (the mother) 'She stayed in Holy water, she disappeared form me', she was brought in a stretcher, all her arms and legs was not functional, all her lips was cracked and all sore. She came in such state….yes, they become like this, they are hurt, since it is a resistant virus it kills them that is how…they are weakened to the point they need intravenous treatment". Another patient said "I went to holy water but when I got sick I came back". The other patient explained it as "…I discontinued and went to holy water. And then when it is not working, I got too sick and that herpes Zoster erupted on my thigh, all around here, then they brought me here and I got treated. ". When asked what problems she faced because of discontinuation of ART, another patient said "You will see the problems you used to face before you started taking the medication after you stopped for 2 to 3 days."

Solutions proposed

Enrolment into PLH associations and sharing life experiences from peers would help. “Yes it helps, They find their peers, hear ‘I have taken it for these years….and I am good’, they will think , be convinced that I will also be like this.” Another solution proposed is to improve the care and support to PLH at facility level. “In order to decrease it [loss to follow up], there should be support, people who discontinued would come for the support”. Another solution proposed is support and follow up by HBC workers.

Giving education in holy water areas is another intervention proposed, different persons have different views on who should give the health education on these areas. Some prefer the religious leaders and others prefer PLH peers. Education is recommended to be given to religious leaders as well. Many PLH will be willing to educate about holy water and medications. One of the interviewees was discussing her experience when she went to a holy water area after her restart and saw a lot of ARV medications [of people who discontinued] hanging and she thought “Should I teach them about what happened to me, I would have been happy if I could explain to them”

For food problem, abolishing the BMI criteria or revising it to include more number of patients is suggested by all.

Discussion

The quantitative part of the study used secondary data collected for routine care purposes. Data completion rate was relatively good considering the chronic problem of Health information system in the country. This is probably because chronic HIV care has started in a relatively more vertical Health Information System with its own standard formats and charts. But completeness of all data is still problem in many charts or questions. Sensitive data like sexual behavior, disclosure status are more incomplete. This is probably because of lack of appropriate facilities for privacy and confidentiality in the health facilities or lack of adequate time of health workers due to patient overload.

The characteristics of the study cohorts is not expected to differ significantly from the population of all ART patients in the Hospital, as the cohorts represent a larger proportion of the general ART patient population in the Hospital and no known systematic change occurred in selection or enrolment of patients to the Hospitals ART clinic. Hence the study findings are generalize able to ART patient population in the Hospital.

The average weight of the study population is 50.6 kg and average BMI is 19.3 and median of 19.14, but 11.1% and 43% of patients have BMI less than 16 (Severe malnutrition) and 18.5 (any form of malnutrition) indicating the huge magnitude of chronic energy deficiency in adults living with HIV.

86.9% of patient classified as WHO stage 3 or 4, 71.7% in functional status of working or bed ridden and average CD4 count at start of ART of 113 and median of 102 are all clear indications

of the problem of late presentation common to all ART programs but more severe problem in developing countries.

Loss to Follow up

Younger age is an independent predictor of loss to follow up even after adjustment for multiple factors unlike the Jimma and Johannesburg Loss to follow up studies (23 ,26). Older age people are expected to be more responsible, take less of substances and hence be better adherent to the treatment program.

Men and women have similar rates of LTFU in this study which is a similar finding with the Jimma and Johannesburg study but there are some studies which reported better adherence in women (17).

Higher education level was almost protective of LTFU in the univariate analysis but the significance disappeared when adjusted for multiple factors (p=.06, HR=1.66(.973, 2.83)).The significance is diluted probably because too many factors are considered in the model, for which the study is not adequately powered. Marital status was found to have no association with LTFU, but as there is no update of the exposure status (changes in marital status are not updated in the chart), it is difficult to evaluate effect of marital status. Changes in marital status will dilute the exposure – outcome association and tend to bias it towards the null.

Providing care giver information, which is a combination of two variables, having a care giver and being able/ willing to provide that is protective of LTFU, but again this association is hidden

in the multiple cox regression model as the number of patients who did not provide this information was not adequately large enough.

Higher Weight and BMI were slightly protective of LTFU in the crude analysis but not in the adjusted analysis. Weight is shown as independent predictor of mortality in many studies, but not of LTFU. Attempts to differentiate between LTFU and death in the outcome by tracking telephone calls, and inclusion of the deaths in the analysis would make the distribution of low weight dying patients uneven, and may affect the results. Adjusted analysis after removing the deaths has slight protection (OR=.970, CI: .956, .984).

Working functional status is protective of LTFU as compared to bed ridden patients, even after adjustment for multiple factors. This is expected as bed ridden patients may not be able to come to the Hospital by themselves and especially if they have not disclosed, they may end up being lost. Some of the bed ridden patients who are classified as lost may actually have died, telephone calls to verify the outcome are not always successful. This association is also observed in the Jimma study.

Lower baseline CD4 increases risk of LTFU, true in the non parametric test as well as the cox regression model. The persistence of this relation after removing the deaths indicates that the risk is not explained by more deaths misclassified as LTFU in the low CD4 category alone. The regimen of ART and time (year) of start of ART has no association with LTFU. This indicates LTFU remains to be problem in all patients and all times. As there had been no intervention addressing LTFU in the time the study is concerned, no change in LTFU is expected.

Among the social and behaviour data in the crude analysis, Working full time, , disclosure, Good Knowledge about HIV and having concern about forgetting to take medications or any concern about adherence are protective of LTFU while having casual sexual partner and having community support increases its risk. Community support appeared to be a risk most likely because most of the patients reporting to have a community support are from Missionary of Charity, a charity organization caring for the homeless and sick people.

Adherence concerns and LTFU

Five adherence concerns are cited by patients (given as choices in the chart), but as only 29.1% of patients cited any concern, and when this is distributed to the five categories each became too small to attain statistical significance. Hence a wide but positively skewed CI spanning zero is observed, except for forgetfulness, which has adequate sample size to attain significance by its own. When all concerns are combined into any concern, there is statistical significance, having a concern is protective of LTFU. This significance persisted even after adjustment for other variables. Moreover, as the number of concern increases, there is a trend towards decreasing LTFU although this was not statistically significant after adjustment. This could be because patients with concern(s) would take more precautionary measures like adherence aids, adherence buddies or seek other supports. Another interesting observation is the difference in the direction of effect and the type of concern. Patients concerned of stigma and afraid of medications have negative effect on follow up while those concerned about forgetfulness and dought about the medications effectiveness show a positive effect on follow up.

Disclosure and LTFU

The same problem occurs in analyzing disclosure (sample size issues in analyzing disclosure to specific groups VS taking just disclosure). Wide CI due to inadequate sample size is overcome by combining all disclosures. As expected, those disclosing have better chance of survival without LTFU, and this is statistically significant in the crude analysis but this is attenuated when multiple variables are included (HR=1.32, CI: .844, 2.01). Interestingly, disclosure to specific people has different effects. Disclosure to spouse has the strongest protective effect followed by to siblings, while disclosure to children, relatives or friends seems to have no effect. Paradoxically, disclosure to parents appears to increase risk of loss to follow up. But none of these effects attained statistical significance alone.

Conclusion and Recommendation

The incidence of loss to follow up from the ART program of St Peters Hospital is very high at 30 per person per year. Important predictors of loss to follow up include age, functional status, baseline CD4 count, and knowledge about HIV. Other factors which are important but did not attain statistical significance in the multivariate analysis due to limited sample size include disclosure status (especially to spouse), adherence concerns.

Patients face significant stress when knowing their HIV status and this precludes from seeking appropriate care treatment on time. Fear of knowledge of HIV status by others, fear of ARV side effects, fear of stringent adherence requirements, and stigma, uncertainty about the future are among the important concerns faced by patients. Reasons for discontinuation of ART include

going to holy water, poverty and lack of food, going to the regions for “personal” reasons, and substance use especially among the youth and young adults.

High priority should be given to address the huge problem of LTFU. The government and other stakeholders should expand the initiatives to reduce LTFU from ART programs. Interventions should focus on high risk groups like younger patients, and patients with advanced disease and patients with specific concerns. It is also necessary to work on important and modifiable risk factors including improving knowledge on HIV. Lower rate of disclosure to spouse coupled with its effect on loss to follow up make it an appropriate target for intervention.

Another important area to address is Holy water. Patients go to holy water seeking cure and to satisfy their spiritual needs. Initiatives to acknowledge use of ARVs with the Holy water should continue and be expanded. But it is also important to recognize and if possible address the spiritual needs of patients at Health facilities. Treating patients as whole person should include not just treatment of the physical disease or the bug, but the social, psychological, physical and spiritual ailments as well. The health sector in our country as it stands now is not organized to address this set of needs and most Health care workers do not recognize addressing spiritual need as part of comprehensive patient care. Hence this would require paradigm shift in thinking and cooperation of multiple sectors.

Poverty and food insecurity complicate appropriate care of a chronic disease. Politico economical approaches would address these problems in general in the country in the long term. But ART treatment programs should be coupled with income generation and livelihood programs for a short term solution.

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Addis Continental Institute of Public Health-UoG
data abstraction format for a study entitled

Assessment of the Magnitude and Factors Associated with Loss to Follow up in the ART Program of St. Peters Hospital, Addis Ababa

Card no (MRN)_____ unique ART no _____ Completed by:_____

Sociodemographic data Date:_____

1	Age	_____yrs	2	sex	1. Male 2. Female
3	Marital Status	1. Never Married 2. Married 3. Separated 4. Divorced 5. Widowed	4	Educational Status	1. No 2. Primary 3. Secondary 4. Tertiary
5	Religion	1. Muslim 2. Orthodox 3. Prothestant 4. Catholic 5. Other	6	Occupation	
7	Children at home	1. Yes 2. No If yes Number	8	Residence (subcity/ woreda)	
9	Care giver information provided	1. Yes 2. No			

Clinical data

10	Height(cm)		11	Weight(kg)	
12	Functional Status	1. Working 2. Ambulatory 3. Bed ridden	13	WHO stage	1. One 2. Two 3. Three 4. Four
14	CD4 count at ART start		15	Initial ART regimen	1. 1a 2. 1b 3. 1c 4. 1d
16	ART start date (dd/mm/yyyy)		17	Side effect of ART	1. Yes 2. No
18	6 month	Wt_____ CD_____	19	12 month	Wt_____ CD4_____
20	Last actual visit date		21	Last appoint ment date	
22	Outcome	1. On FUP 2. Restarted 3. Lost 4. TO 5. Dead			

Social, Behaviour and Knowledge data

23	Current employment	1. Working full time 2 .Working part time 3. Not working due to ill health 4. Unemployed		24	Number of rooms		
25	Number of people in the household			26	Community support HIV support group	1. Yes 2. No	
27	Disclosure	1. No 2. Wife/husband 3. Own child/ren 4. Parents 5 . Brother/sister(s) 6. Relatives 7. Friends		28	Understanding of HIV disease	1. NA 2. - 3. + 4. ++ 5. +++	
29	Understanding of HIV tranismision	1. NA 2. - 3. + 4. ++ 5. +++		30	Understanding of prophylaxis and treatment of OI	1. NA 2. - 3. + 4. ++ 5. +++	
31	Understanding of ART medication adherence	1. NA 2. - 3. + 4. ++ 5. +++		32	Has regular sexual partner	1. Yes 2. No	
33	Has casual sexual partner(s)- number of casual partners in last 3 mo	1. 0 2. 1 3. 2 4. 3 5. >3		34	Tobaco use	1. Yes 2. No	

35	Alcohol use	1. Yes 2. No		36	Soft drugs	1. Yes 2. No
37	Hard drugs	1. Yes 2. No		38	Adherence concerns	1. Stigma 2. afraid of medications 3. Dought that medications will work 4. depressed/anxious 5. will forget to take medications 6.other:_____

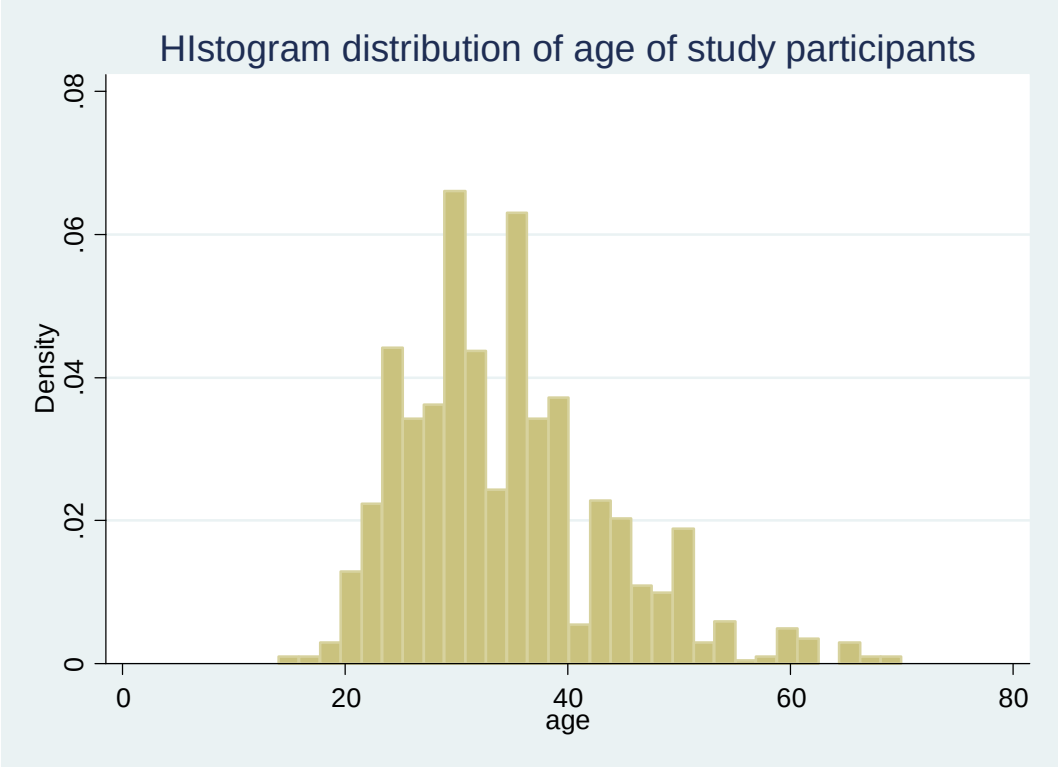
Appendix 2: Detailed analysis, Univariate and bivariate for remaining variables

Sex

More participants are female (55.3%). Chi-square test was used to test for association between sex and the outcome (All assumptions for Chi square statistics are fulfilled, and without regard to the follow up time to test only for cumulative risk) and it didn't reveal any significance (p=.730)

Age: Data on age is obtained from 1079 participants (98.5%). The mean is 34.5 and Median is 33.The youngest is 14 years and oldest one is 70. The distribution appears fairly normal with the following Histogram. But there is some clustering of the values at multiples of 5. The conservative normality tests of Kolmogrov- smirnov and Shapiro-Wilk revealed that the distribution is not normal (p=0.000), and the Normal Q-Q plot also shows deviation from the expected line. Hence non parametric test and binary logistic regression is used to test for association between age and the outcome, loss to follow up.

Fig : Histogram distribution of age at enrolment of study participant, June 2009, St peters Hosp, AA

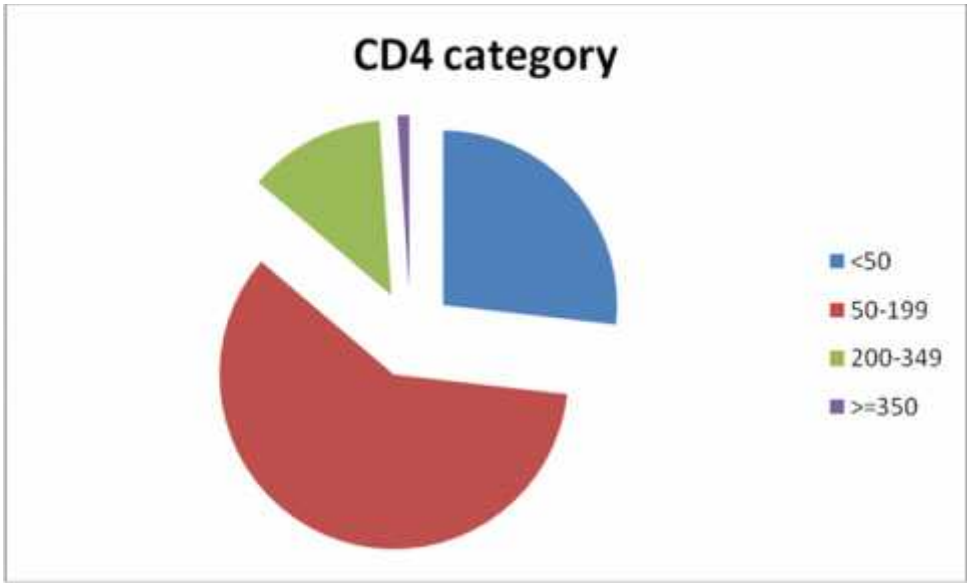


The binary logistic regression showed significant inverse association between age and loss to follow up, with about a 2 % decrease in loss to follow up for a unit (one year) increase in age. (p=0.003, OR=.978 (.964,.992))

Baseline CD4

It is available for 99.9% of cases. It has a mean of 112.99 (SD: 79.434), CI: 108.27,117.70. The median is 102.0 (IQR: 48, 166) and it ranges between 1 and 536. Its skewness is high at 1.001. The normality tests , histogram and Q-Q plots all show a left skew, hence non parametric statistics is appropriate for this variable.

Fig : Pie chart, CD4 count at start of ART, St Peters Hosp, AA



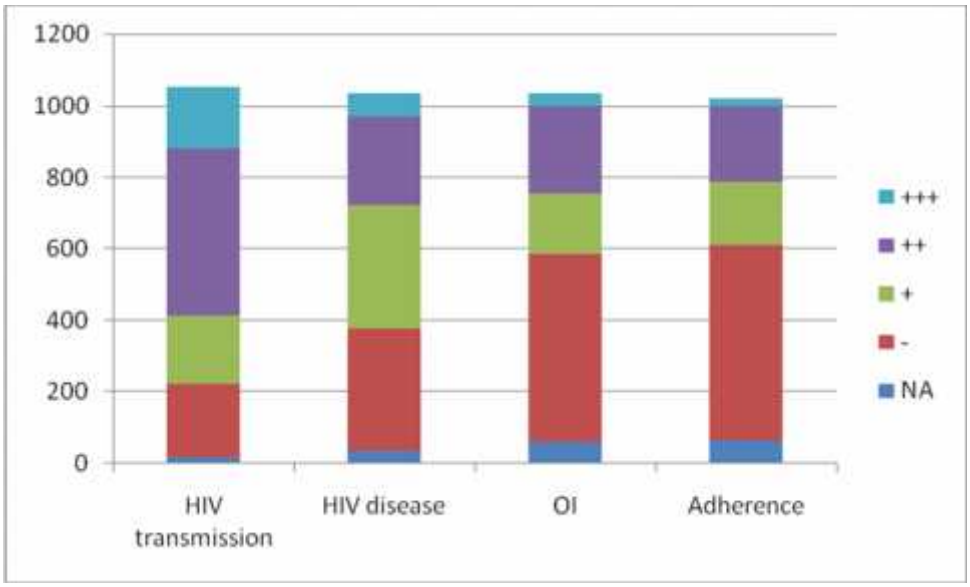
In the non parametric Mann-whitney test, mean ranks for lost and not lost is 517.98 and 558.17 respectively and there is a significant inverse relationship between baseline CD4 and loss to follow up., z=-1.999, p=.046.

Baseline CD4 was also analyzed excluding deaths, using non parametric statistics. 921 cases were available for analysis. The mean, median and inter quartile range did not change significantly, median=111 (IQR: 54,172). Mean ranks for lost and not lost groups was 412 and 493 respectively and the strength of the association as tested by Mann- Whitney test increased, z=-4.507, p=.000

Knowledge of HIV and ART

Knowledge of patients is assessed at enrollment using four variables: Understanding HIV disease, understanding HIV transmission, understanding prophylaxis and treatment of OIs and understanding ART medication adherence. The response is rated by the counselor (1) as NA, (2) as -, (3) as +, (4) as ++, and (5) as +++. When compared among these variables, patients at enrollment have a better understanding of HIV transmission and HIV disease than OIs and adherence. Median knowledge rate was 4 for HIV transmission, 3.0 for HIV disease, 2.0 for both OIs and adherence.

Fig : Stacked bar chart for knowledge comparison of the four categories of knowledge on HIV, June 2009, St Peters Hosp, AA



X2 statistics was applied to test association of understanding of each variable with the outcome after NA responses are excluded and OR is computed from binary logistic regression. Understanding HIV disease showed significant correlation, better understanding being protective, p= .013, OR: .786 (CI: .679,.911).The association is even stronger for understanding of HIV transmission, p=.004, and the those with their knowledge rated as (-) are twice more likely to be lost compared those rated as +++ , OR=2.086 (1.337, 3.255).

Understanding about OI did not show any significant correlation with the outcome, p=.776, OR (.829, 1.102). This was also true for understanding about adherence too, p=.584.

Sexual Behaviour and Adherence Concerns

These variables are of the most incomplete ones in the charts. Question on having a regular partner is filled in only for 53.7% and data on casual partner is available only for 19.7% . Of these 46.9% responded positively as having a regular partner and 67.6% of those filled in responded as having one or more casual partner in the last 3 months. The mean number of casual partners for those responded was 2.33, and the median is 2.00 and It ranges between 1 and 5 . Of those with regular partner, data on casual partner was available for 65 of 277 cases. Of these 65 cases, 46.2% had one or more casual partners in the last 3 months before enrollment and 5 (7.7%) had more than 3 partners in the same period.

Table : frequency distribution of number of Casual partners for those with regular partner and number of adherence concerns

NumberOfcasual partners		Frequency	Percent	Cumulative Percent
	0	35	53.8	53.8
	1	19	29.2	83.1
	2	2	3.1	86.2
	3	4	6.2	92.3
	More than 3	5	7.7	100.0
	Total	65	100.0	
Number of concern				
	0	776	70.9	70.9
	1	296	27.0	97.9
	2	16	1.5	99.4
	3	6	.5	99.9
	4	1	.1	100.0
	Total	1095	100.0	

Having regular partner or not was not associated with being lost to follow up on X2 statistics, p= .740, OR (.661, 1.342). But having a casual partner was a risk for loss to follow up, p=.013, OR: 2.554 (CI: 1.196,5.455). The number of casual partners one have showed marginal significance, p=.051.

About 97.7% cases have data on adherence concerns. Stigma (7.5%), afraid of medications (5.5%), dought that medications will work (1.8%), depressed/ anxious (1.3%), will forget to take medications(16.6%) are cited as concerns.29% of patients cited one or more concerns, and only 2.1% cited 2 or more concerns.

On x2 statistics, none of these cited concerns showed statistical significance alone except the concern about forgetting to take medications (increases risk) but having any concern is significantly increases the risk of loss to follow up.

Marital Status Educational Status and Religion

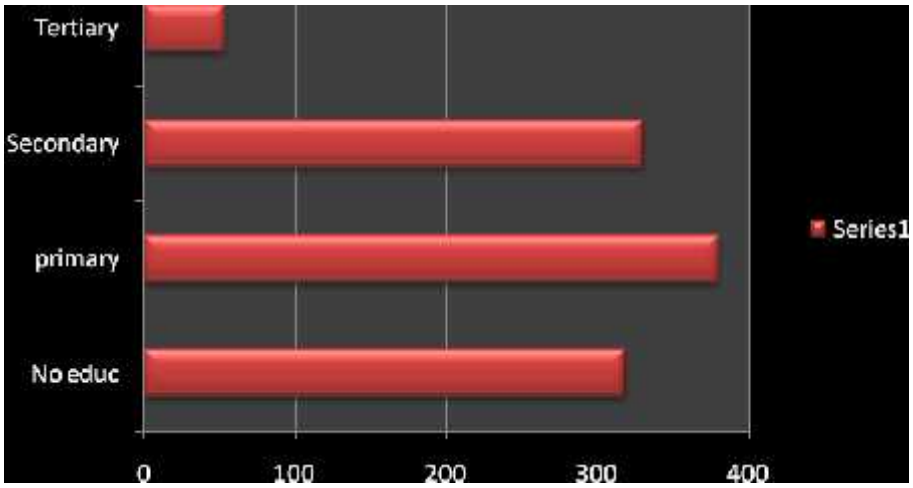
Married, primary education and orthodox religion are the commonest responses in these categories. Data is obtained in 99.2, 98.8 and 98.9 percent of cases respectively. As categorical variables, X2 test is used to test for association, and educational status (p=.001) and religion (p=.009) showed significance. Binary logistic regression is used to find out the crude OR. Those with No education have a 90% more chance of loss to follow up as compared to those with tertiary education (OR=1.918, CI 1.016-3.622).

Table : logistic regression of selected variables on loss to follow up

	B	S.E.	Wald	Df	p	OR	95.0% C.I.for OR	
							Lower	Upper
Educational status			16.822	3	.001			
No Education	.651	.324	4.033	1	.045	1.918	1.016	3.622
Primary	.242	.323	.563	1	.453	1.274	.677	2.400
Secondary	-.002	.328	.000	1	.996	.998	.525	1.898
Tertiary						1		
weight	-.018.	.007	7.298	1	.007	.982	.969	.995
Age	-.022	.007	9.115	1	.003	.978	.964	.992

In the logistic regression test of religion on the outcome it was found out that orthodox Christian followers are twice more likely to be lost to follow up as compared to Catholics (p= .014, OR= 2.024, CI: 1.153,3.614).

Fig : Bar graph for educational status at enrolment of study participant, St peters Hosp, AA, June 2009



Children and their Number

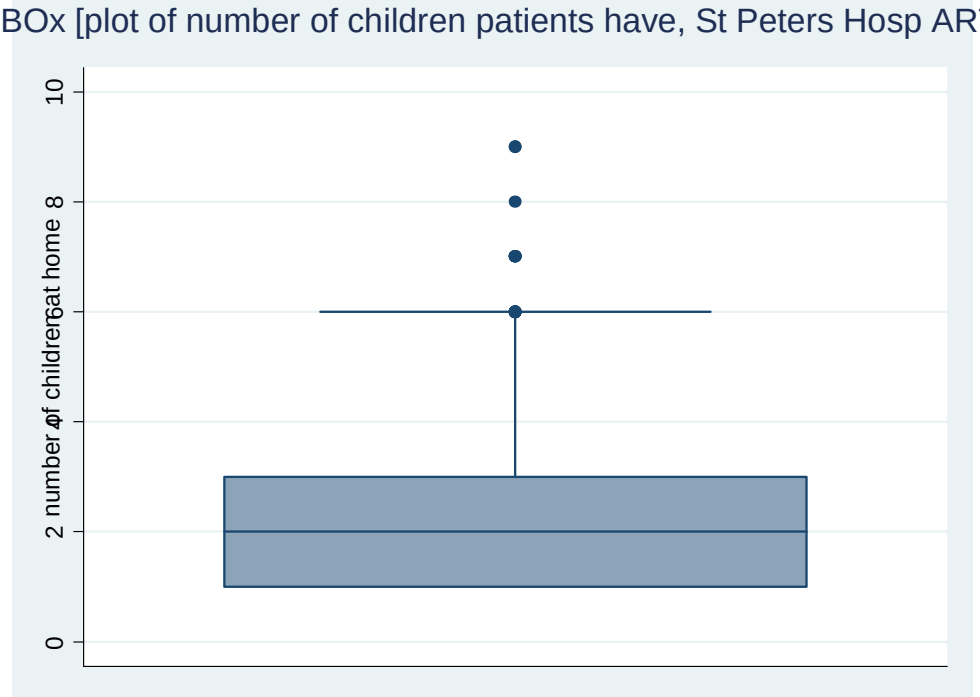
Data was also collected on whether participants have children and how many children they have. This information was complete in 92.5 % of cases and 58.9% have children, of these majority have one or two child/ren, 37.8% and 31.1% respectively. Only less than 10% have 4 or more children. Those with children are at a slightly higer risk of loss to follow up than those without, p=.04, OR: 1.313, CI: 1.o12,1.704.

Table : frequency distribution of number of children patients have at enrollment , St peters Hosp, AA, June 2009

Number of children	Frequency	Percent	Cumulative Percent
1	129	37.8	37.8
2	106	31.1	68.9
3	50	14.7	83.6
4	30	8.8	92.4
5	10	2.9	95.3
6	8	2.3	97.7
7	5	1.5	99.1
8	1	.3	99.4
9	2	.6	100.0
Total	341	100.0	
Total	614		

The distribution of the number of children is highly skewed to the left with all the tests and histogram and box plot showing a non normal distribution. Hence non parametric test is used to test for association of number of children (after selecting cases with only “Yes” response to the question “do you have children?”). The test showed no significance with mean ranks of 171.67 and 172.67 for the not lost and lost to follow up groups respectively, p=.927.

Fig : box and whisker plot of number of children patients have at enrolment , St peters Hosp, AA, June 2009



Care giver information

90.5% Of patients had provided care giver information and documented on their charts. The X2 statistics showed significant correlation between providing this information and loss to follow up, p= .001. Those without this information are twice more likely to be lost from follow up than those whose care giver information (address) is documented OR=2.028, CI: 1.341, 3.066.

Weight and Height

Height is available only for 82.7% of cases. Its mean is 162.172 cm, CI: 161.57,162.78. The median is 162.0, The shortest person measured 130.0cm and the tallest is 191.0cm. The inter quartile range is 13 cm(156, 169) and the skeweness of the distribution is only .156. The conservative normality tests of Kolmogrov-Smirnov and Shapiro-Wilk ruled that it is not normality distributed but the histogram, normal Q_Q plot and box –wisker plots are very suggestive of a normal distribution.

Fig : Histogram Distribution of height of patients at enrolment, St peters Hosp, AA, June 2009

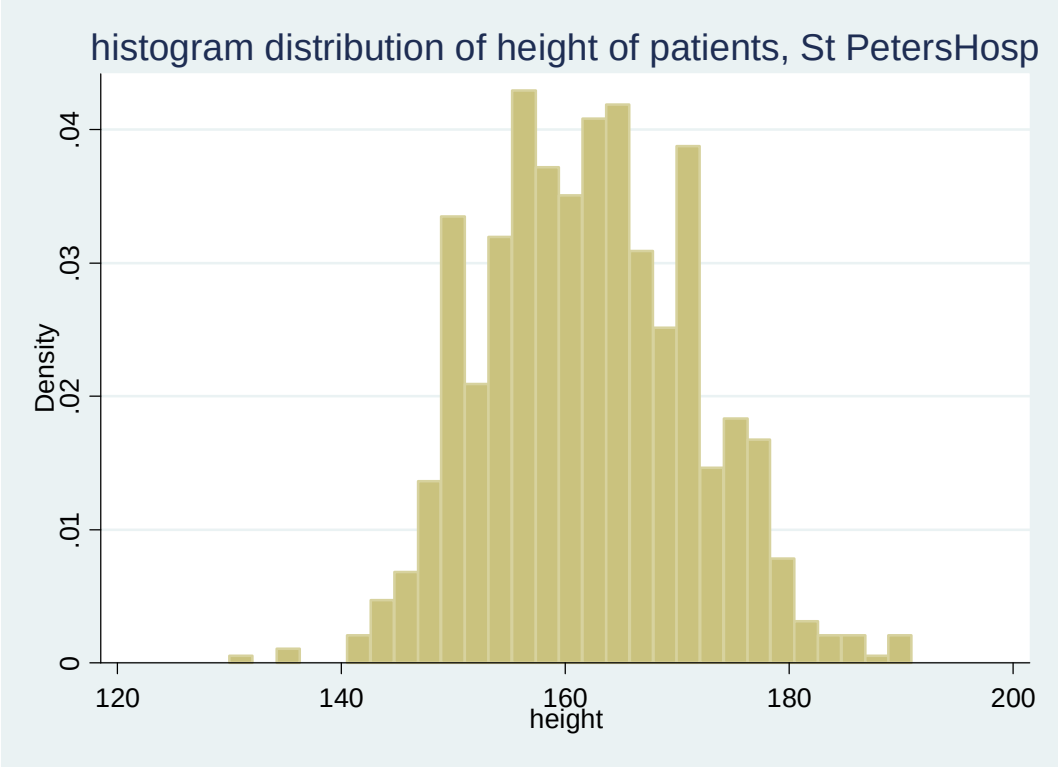


Fig : Normal q-q plot of height of patients at enrolment , St peters Hosp, AA, June 2009

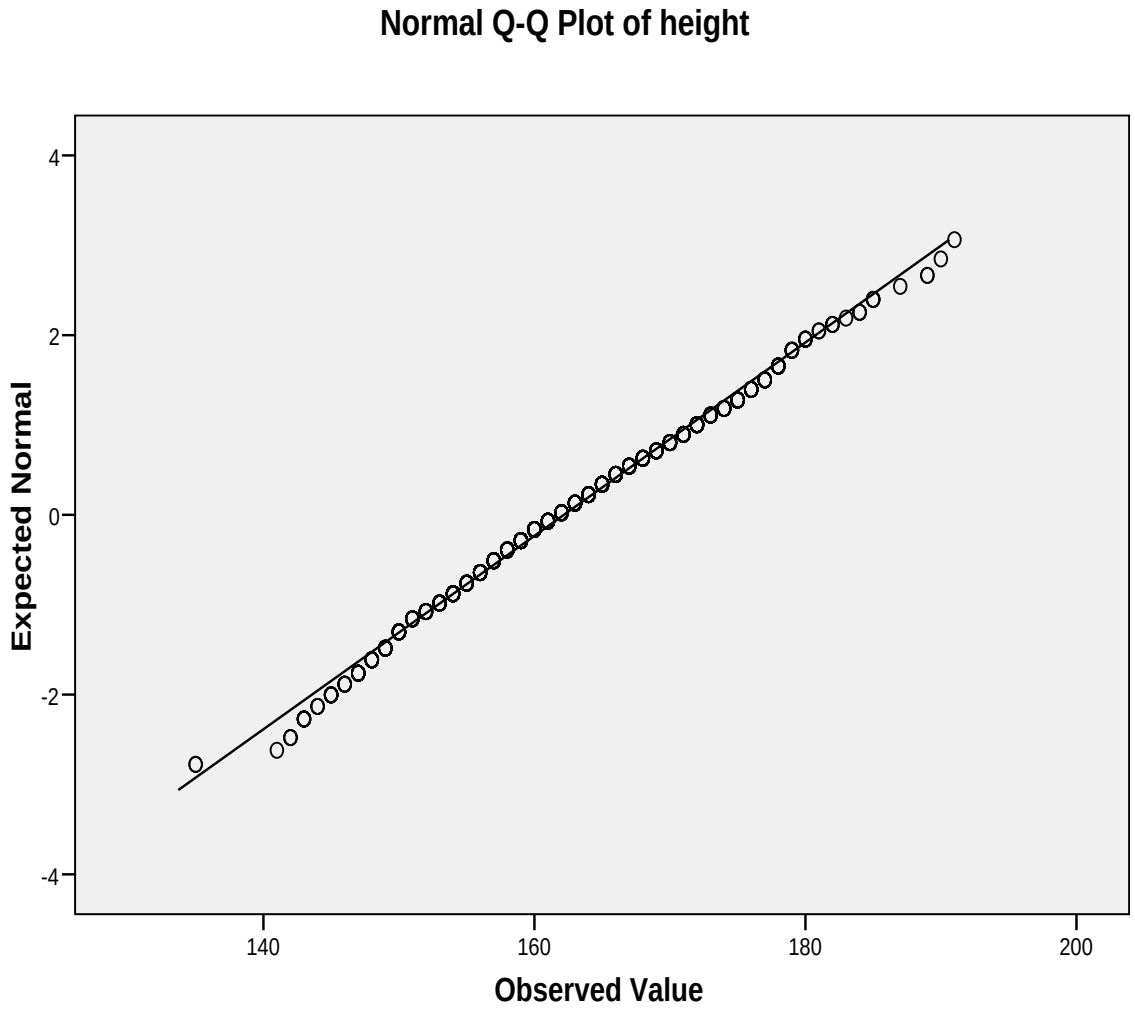
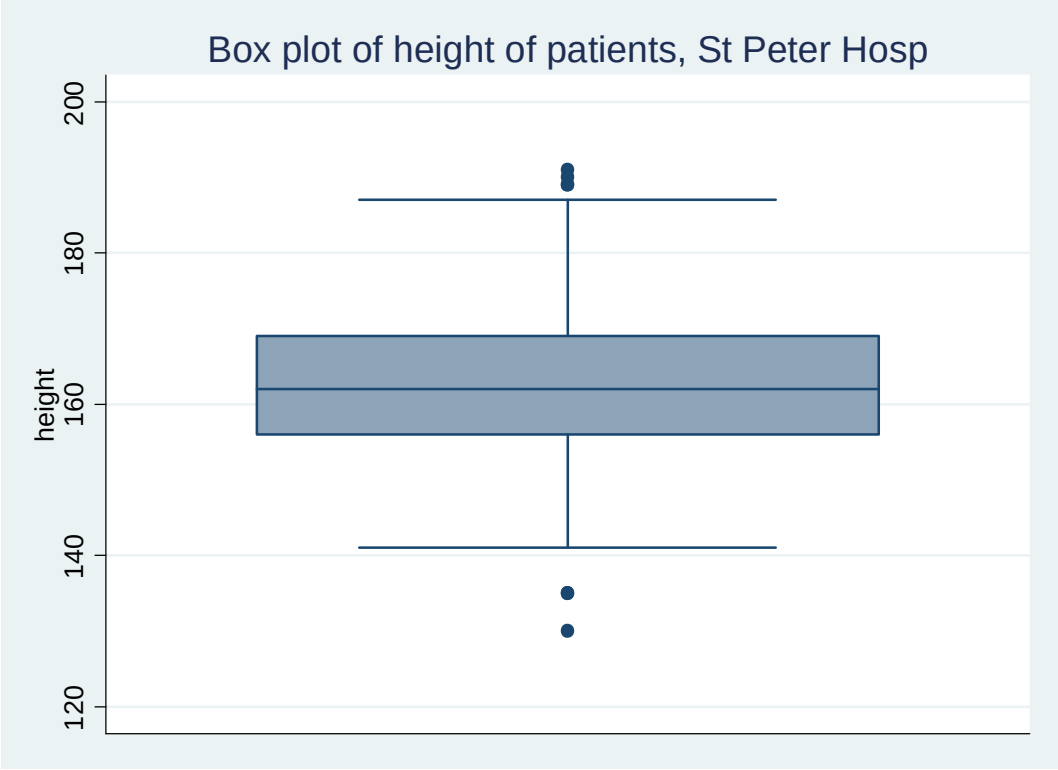


Fig : box whisker plot of height of patients at enrolment , St peters Hosp, AA, June 2009



Logistic regression is used to test for association between height and the outcome and it showed no association (p=.895). The means of those lost to follow up and those not was also compared using 2 sample t-test. Assuming un equal variance (F=.866) the mean difference is .0879 (-1.2187, 1.4144).

Weight data is available for 96.1% of patients. Its mean is 50.596 Kg (CI: 49.99, 51.20). The median is 50.00 (IQR: 44.0, 56.75). The smallest weighs is 20 kg and the heaviest is 89 kg at start of ART and The skewness of the distribution is .459. All of the normality tests showed that the distribution significantly deviated from normal distribution and this is also evident in the Histogram and Q-Q plots. The stem and leaf shows the measurements cluster at multiples of 5.

Fig : weight Stem-and-Leaf Plot of height of patients at enrolment , St peters Hosp, AA, June 2009

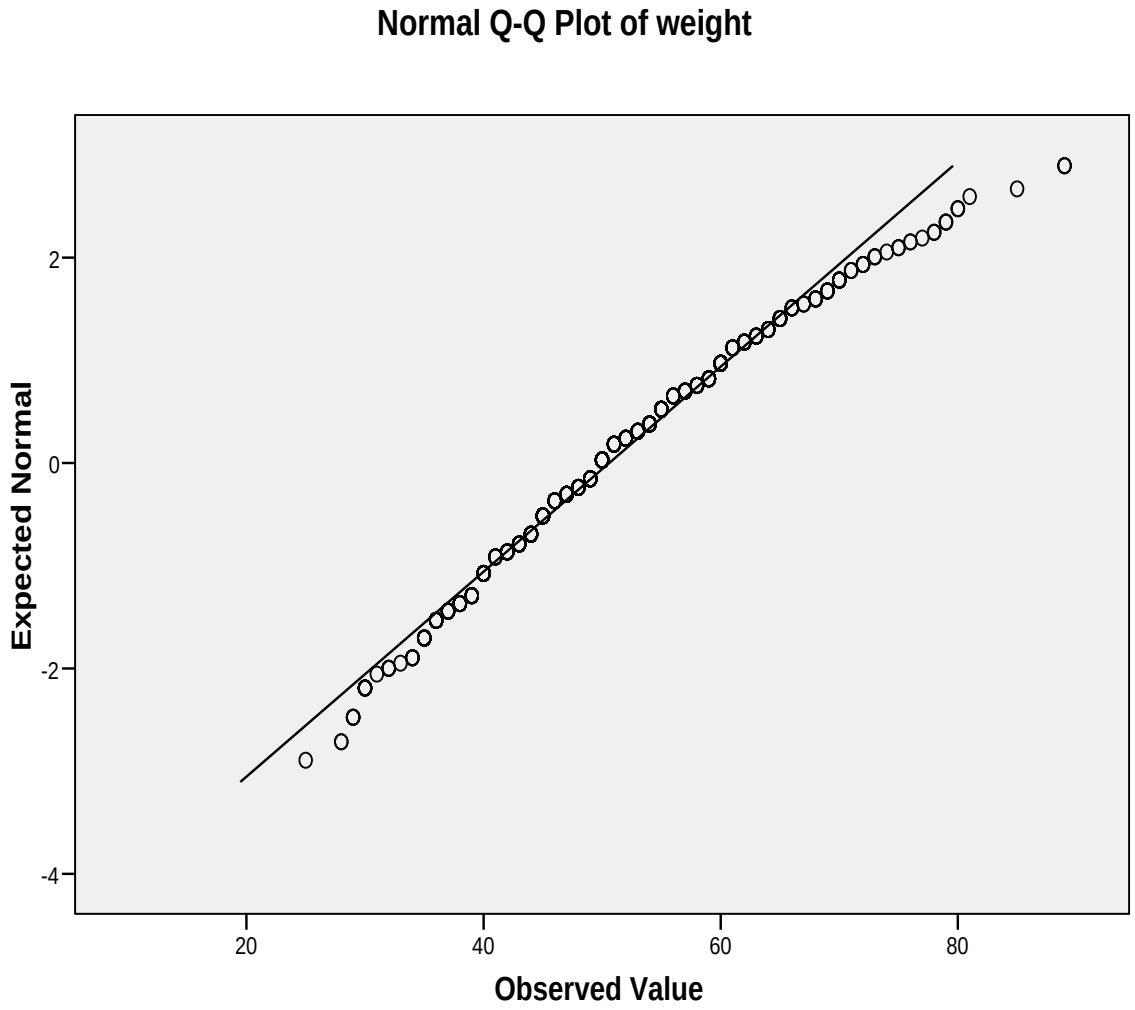
```
 Frequency    Stem &  Leaf

    2.00 Extremes    (=<25)
     .00       2 .
    7.00       2 .  899
   12.00       3 .  0000&
    6.00       3 .  22&
   32.00       3 .  44555555555
   25.00       3 .  66667777
   27.00       3 .  888899999
   83.00       4 .  00000000000000000000000000111
   46.00       4 .  222222333333333
  124.00       4 .  44444444445555555555555555555555555555555
   50.00       4 .  6666666777777777
   69.00       4 .  8888888899999999999999
  128.00       5 .  00000000000000000000000000000000000000111111
   55.00       5 .  222222222233333333
  109.00       5 .  44444444445555555555555555555555555
   32.00       5 .  66666777777
   40.00       5 .  88888899999999
   73.00       6 .  0000000000000000000001111
   24.00       6 .  22223333
   36.00       6 .  444455555555
   10.00       6 .  667
   17.00       6 .  888999
   15.00       7 .  00001
    9.00       7 .  223
    4.00       7 .  5&
   17.00 Extremes    (>=76)

 Stem width:      10.0
 Each leaf:       3 case(s)
```

& denotes fractional leaves.

Fig : normal q-q plot for weight of patients at enrolment, St peters Hosp, AA, June 2009



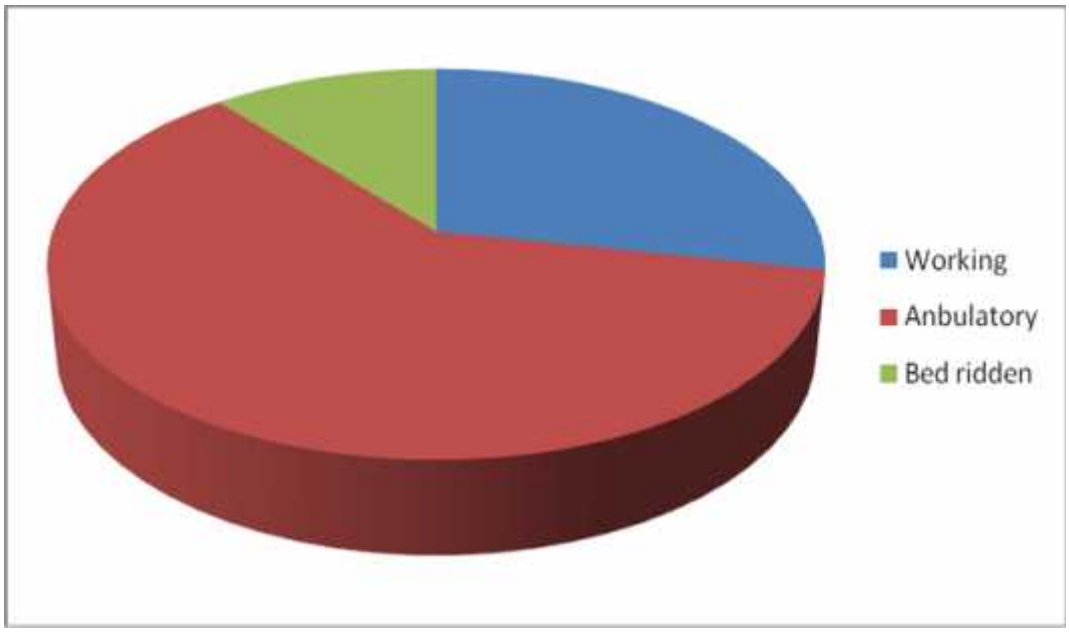
On logistic regression model it is showed that there is a significant inverse relationship between weight and loss to Follow up (p=.007, OR=.982 and CI: .969, .995), a 1.8% decrease in loss to follow up for each kg increase in weight.

In The Non parametric test, the mean rank of those lost and not lost was 488.32 and 542.22 respectively and p is significant at .006.

Functional Status

99% of patients have baseline functional status documented and the majority, 60.8% are in the Ambulatory category.

Fig : pie chart of functional status of patients at baseline, St Peters Hosp, June 2009, AA

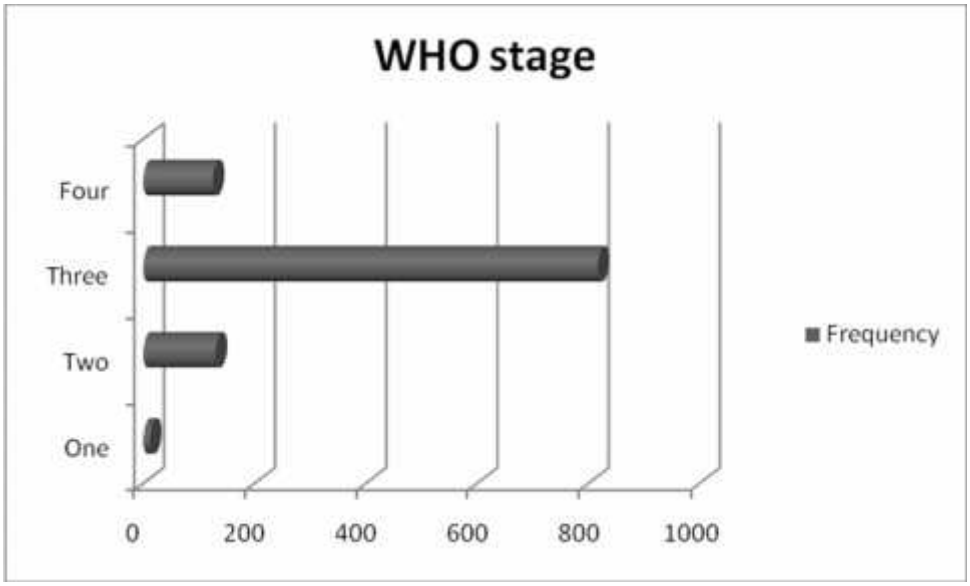


Association between functional status and the outcome was tested using a X2 statistics which showed significance (p=.010) and the OR is obtained by binary logistics regression. Those in the working category have a lower risk of lost from follow up as compared to those in the bed ridden category, OR=.556 (.356, .867).

WHO Stage

WHO stage is documented for 99% of patients of whom 75.4% are in stage 3, and only 1% are in stage 1.The x2 statistic did not show any significant association between WHO stage and the outcome variable (p=.16). This is also true for binary logistic regression model where all the ORs compared with WHO stage 4 did not attain any significance (Stage 1 OR=.16 CI:.02,1.277, stage 2 OR .733, CI: .433,1.241, stage 3 OR.932 CI:.629,1.382)

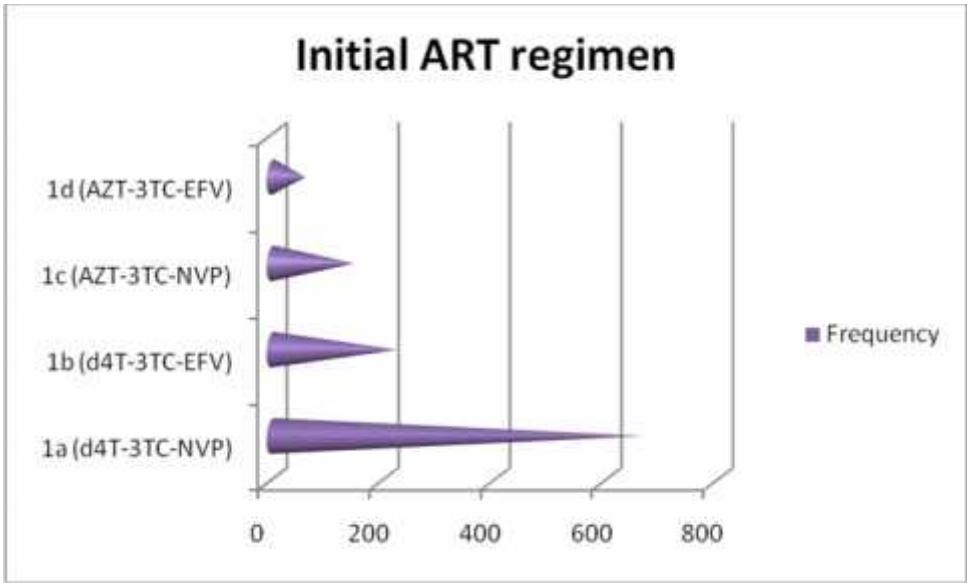
Fig : bar graph frequency distribution for WHO stage of patients at baseline, St Peters Hosp



Initial Regimen

ART regimen started is obtained for all cases. Majority, 60.7% were started on 1a (d4T-3TC=NVP) and only 5.4% were started on 1d (AZT-3TC-EFV).

Fig : Initial regimen of patients by bar graph



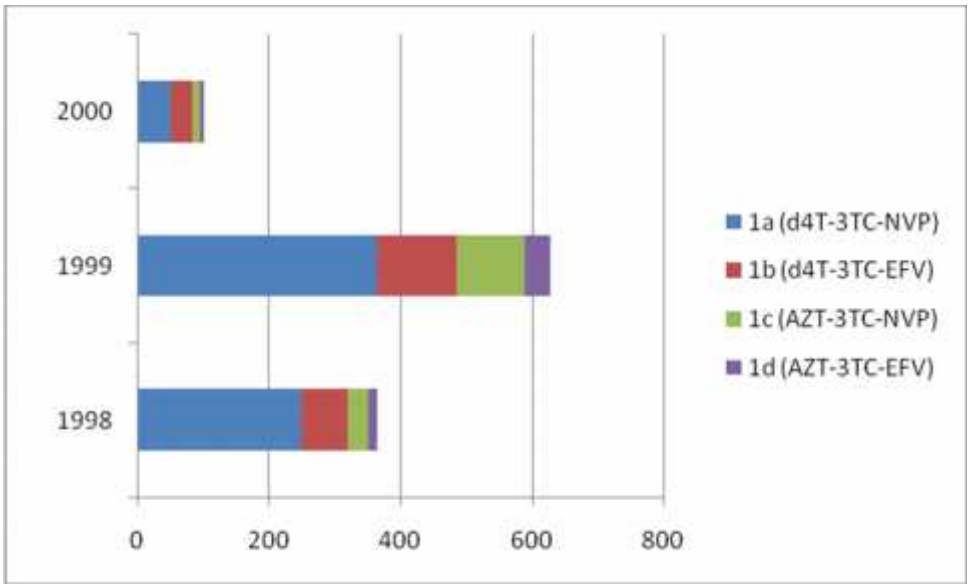
Regimen by time

X2 statistics was used to test association between regimen and loss from follow up and it is significant, p=.022.Odds ratio calculated from logistics regression model showed no significance, but with appropriate coding (lost=1, not lost=0), the means (proportion) of loss to follow up is compared among the four categoties of regimen using ANOVA. The overall test showed significance at p=.022 and the only significantly different pair is between 1a and 1b, p=.023.

Time of ART start

Time (Year) of start of ART start of the cohorts was extracted from ART start date and analysed, 57.4 % of the cohorts started ART in 1999 EC, X2 test was used to see if there is any trend or change in los to follow up over time (years), but the statistics is not significant, p=.911.

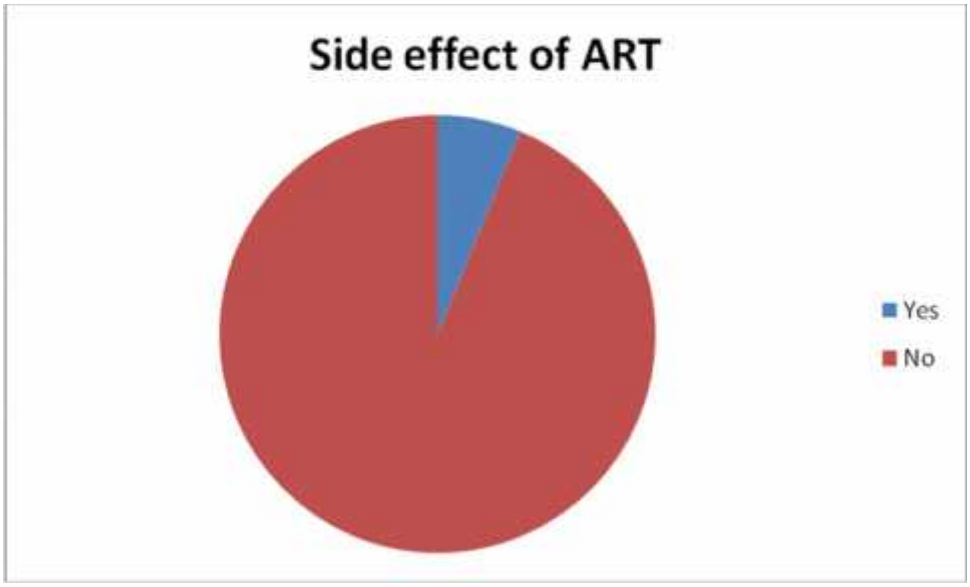
Fig : initial regiment of ART by Cohort year



Side Effect of ART

Side effect data is available only in 72% of the charts and for the vast majority, 93.8%, it is no. The x2 statistics is also insignificant at p=.313.

Fig : side effect profile in a pie chart



Employment

This data is available only for 76.9% cases and the most common response is unemployed, 46.4%. The x2 statistics is significant, p= .032 and odds ratio from binary logistics regression showed that working full time is a protective factor as compare to those unemployed, p=.007, OR=.565 (.375, .853)

Community Support

Availability of Community support is filled in only in 75.1% of the charts of which only 15.7% responded positively. When tested with x2 statistics for association with the outcome, having community support is protective, p=.023, OR=.641 (CI: .463, .942).

HH size and Number of rooms

Number of people residing in the house and number of rooms are among the living condition data collected from the social form. HH size was available only for 79.2 % cases. The mean HH size is 4.05 (SD:2.349 CI: 3.89,4.21), its median is 4.0 (IQR: 2, 5) . It ranges between 0 and 15 and the skew ness is high at 1.041.

Table : frequency distribution of No of People in HH

No of people in HH	Frequency	Percent	Cumulative Percent
0	2	.2	.2
1	110	12.7	12.9
2	134	15.5	28.4
3	146	16.8	45.2
4	156	18.0	63.2
5	127	14.6	77.9
6	74	8.5	86.4
7	48	5.5	91.9
8	27	3.1	95.0
9	18	2.1	97.1
10	15	1.7	98.8
11	3	.3	99.2
12	2	.2	99.4
13	1	.1	99.5
14	2	.2	99.8
15	2	.2	100.0
Total	867	100.0	

The histogram, Normality tests and other plots(Q_Q and box-whisker) all show significant deviation from normal distribution with left skewness and hence non parametric statistics is used to test for association(2 independent samples)

Fig : histogram distribution of number of people in HH

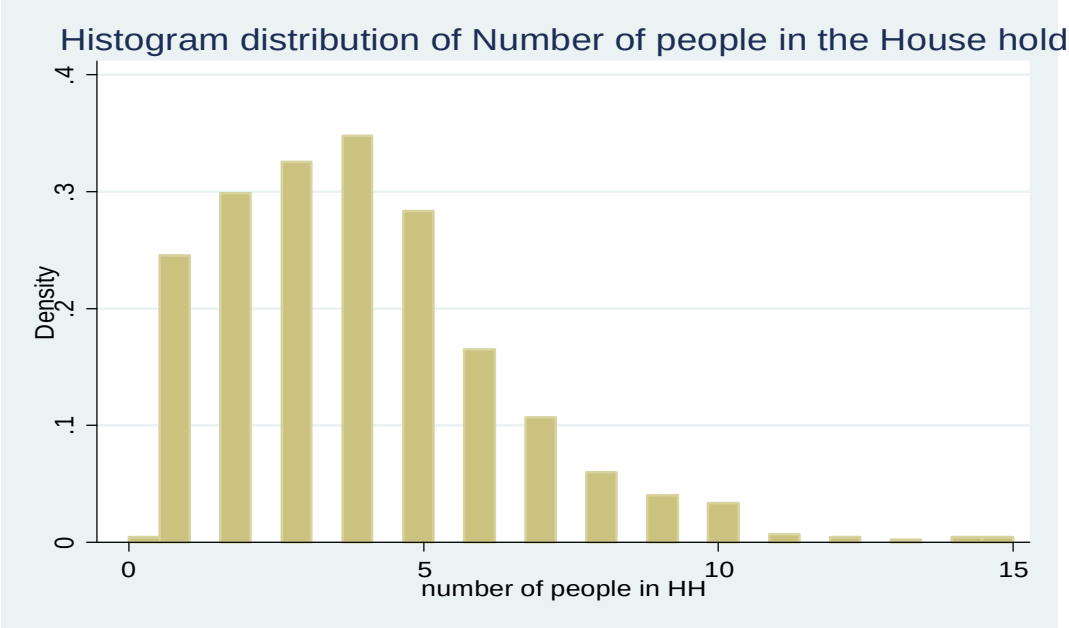
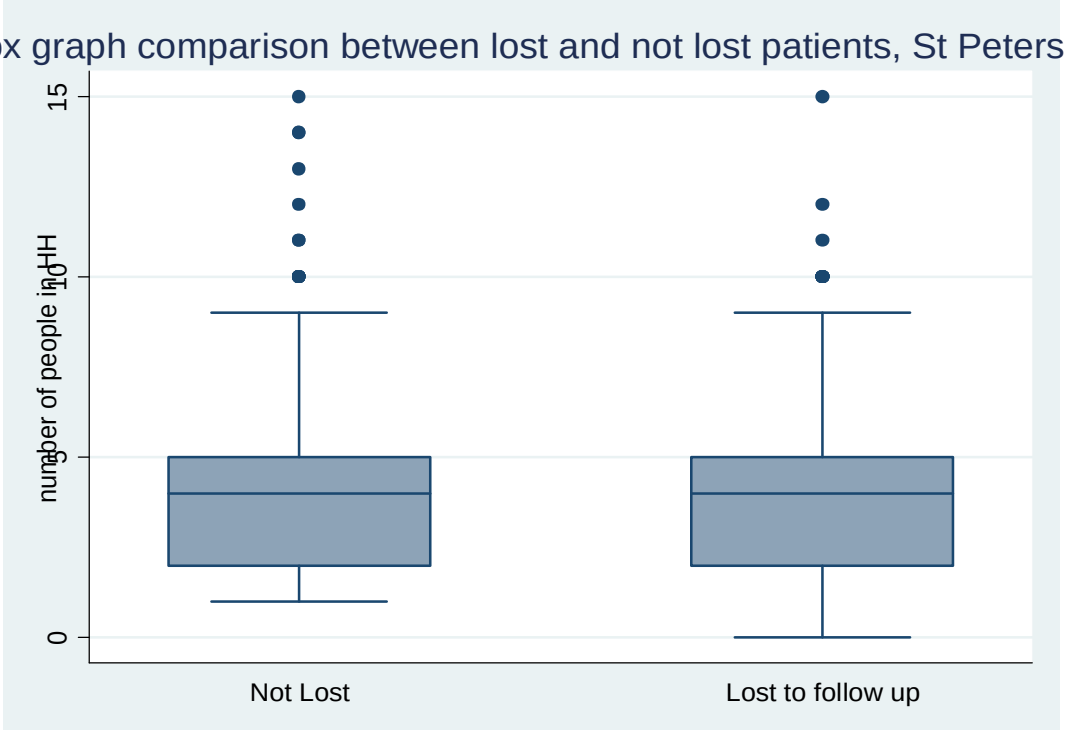


Fig : Box graph of number of people in HH of patients by status of loss to follow up, St Peters Hosp, June 2009, AA



The mean ranks in the Mann-Whitney non parametric test for those with the outcome (lost) and those without (not lost) is 432.95 and 430.58 respectively, p=.940 showing no significance.

Number of rooms people are living in was available only for 80.5 % cases. The mean number of rooms is 1.85 (SD:1.341, CI: 1.76, 1.94), its median is 1.0 (IQR: 1, 2) . It ranges between 1 and 15 and the skew ness is very high 3.452.

The histogram, Normality tests and other plots(Q_Q and box-whisker) all show significant deviation from normal distribution with left skewness and hence non parametric statistics is used to test for association(2 independent samples)

Table : frequency distribution of Number of rooms

	Frequency	Percent	Cumulative Percent
1	465	52.8	52.8
2	239	27.1	79.9
3	109	12.4	92.3
4	33	3.7	96.0
5	19	2.2	98.2
6	4	.5	98.6
7	4	.5	99.1
8	4	.5	99.5
10	2	.2	99.8
13	1	.1	99.9
15	1	.1	100.0
Total	881	100.0	

Fig: Histogram distribution of number of rooms

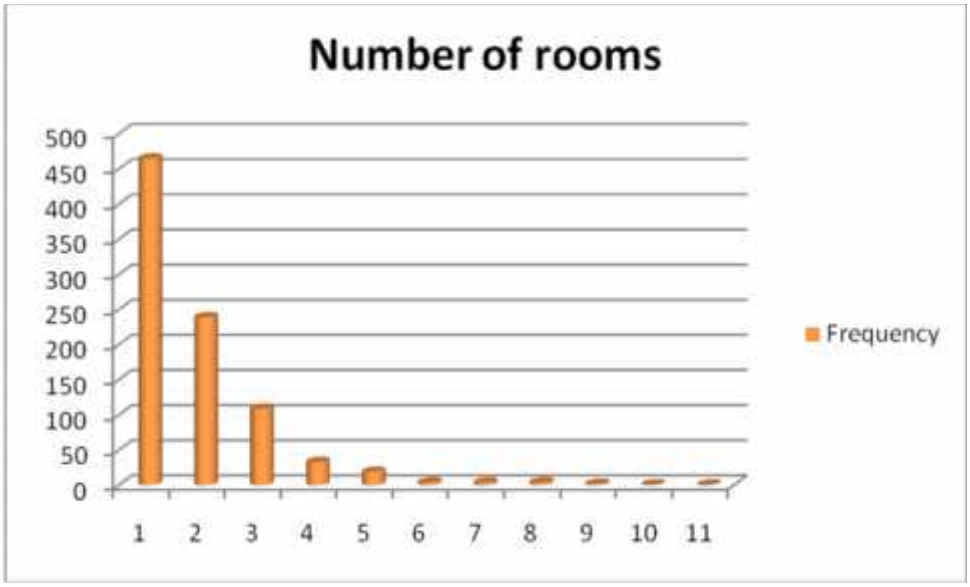
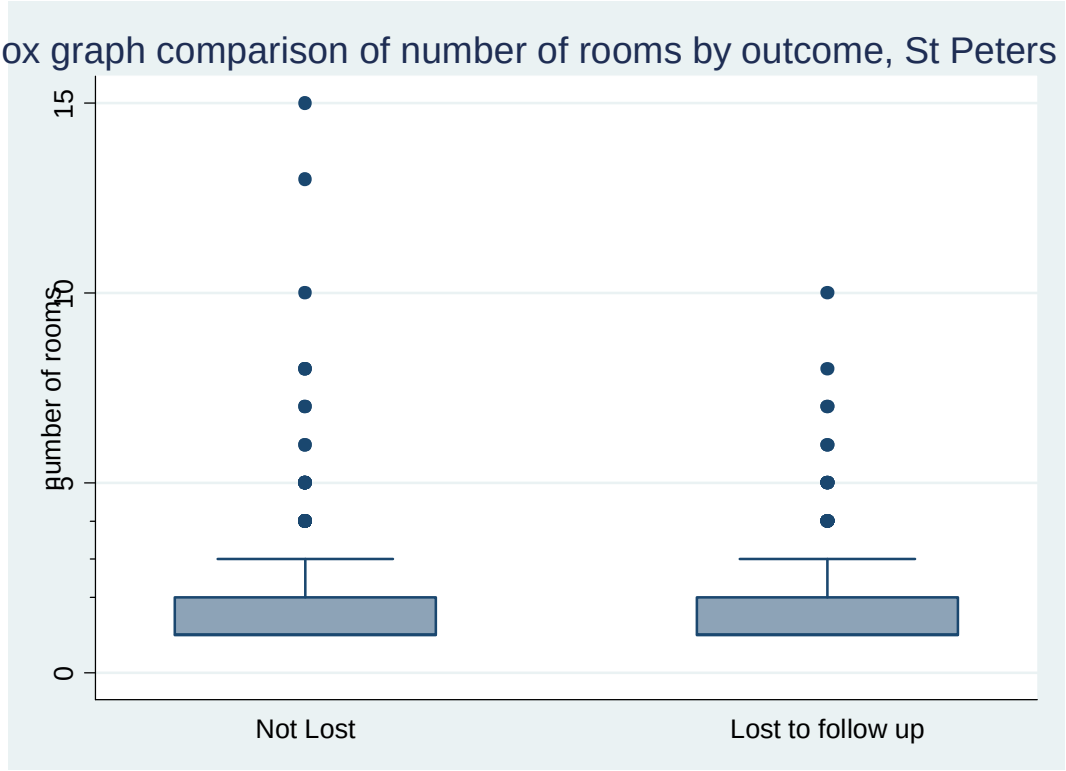


Fig : Box graph of number of rooms of HH of patients by status of loss to follow up, St Peters Hosp, June 2009, AA



In Mann-whitneys non parametric test for 2 independent samples mean ranks of the two groups (lost and not lost) is 422.48 and 445.00, but not statistically significant, p=.181.

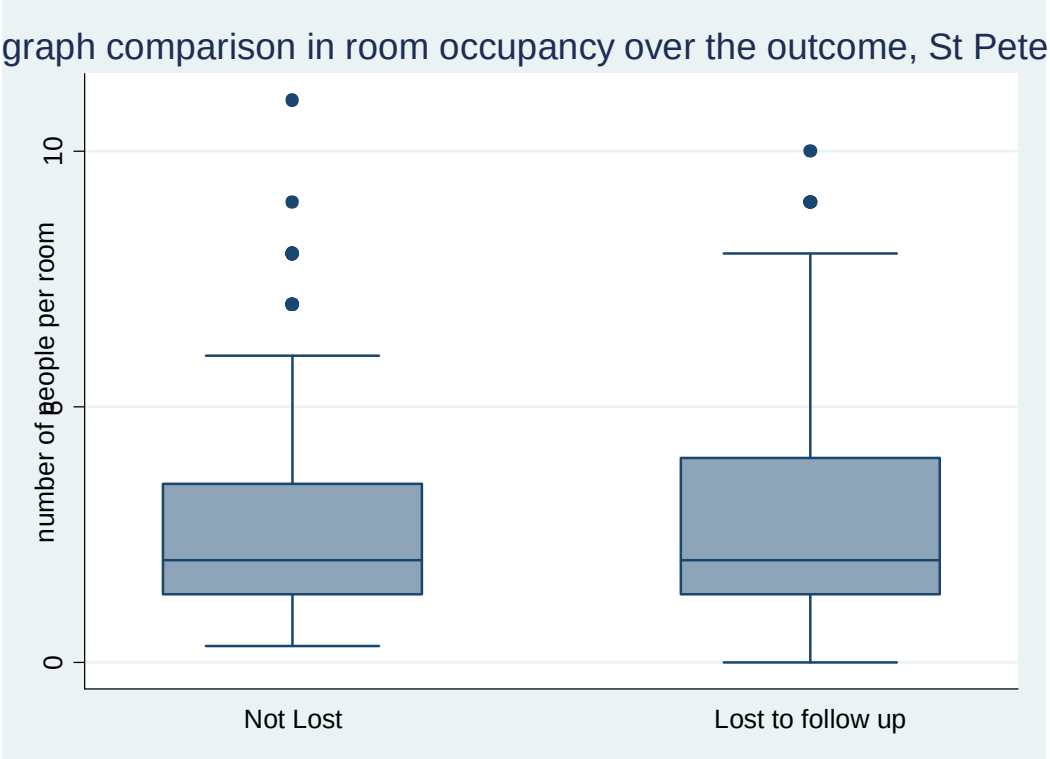
The ratio of Number of people in HH and Number of rooms is taken to see the density or room occupancy. On average 2.65 people live in one room (CI: 2.53, 2.76). Half of the respondents reside for two in a room (IQR: 1.33, 3.50). The minimum ratio is 0 and the highest density is 11 people per room. The skewness is 1.301. All the normality tests show that the distribution significantly deviates from normal.

Fig 23: Stem-and-Leaf Plot for People Per Room in a HH of patients St Peters Hosp, June 2009, AA

```
 Frequency    Stem &  Leaf
    9.00        0 .  34&
   27.00        0 .  56678&
  184.00        1 .  00000000000000000000000000000023333&
   74.00        1 .  555555555666667&
  160.00        2 .  00000000000000000000000000000003&
   49.00        2 .  555555556
  116.00        3 .  00000000000000000000003&
   25.00        3 .  55555
   92.00        4 .  000000000000000000
    8.00        4 .  55
   57.00        5 .  00000000000
    2.00        5 .  &
   22.00        6 .  0000
   26.00 Extremes    (>=7.0)
 Stem width:      1.00
 Each leaf:       5 case(s)

 & denotes fractional leaves.
```

Fig : Box graph of people per rooms in a HH of patients by status of loss to follow up, St Peters Hosp, June 2009, AA



In Mann-Whitney non-parametric test, mean ranks of those lost was 428.91 and for those not lost was 420.37, z=-4.73, p=.636 , showing no significance between room density and loss to follow up.

Substance Use

Data is collected on use of substances: tobacco, alcohol, soft drugs (khat, shisha…) and hard drugs (cocaine, marijuana..). Availability of data is 93.4%, 94.2%, 94.2% and 91.4% respectively. Use of these substances is 14.2% for tobacco, 22.8% for alcohol, 21.1% for soft

drugs and 2.8% for hard drugs. The number of substances used was calculated from the data and it showed that 31% are using one or more of these substances and 2% use all of the four substances.

Table : frequency distribution of Number of Substances Used

Number of substance used	Frequency	Percent	Cumulative Percent
0	756	69.0	69.0
1	139	12.7	81.7
2	93	8.5	90.2
3	85	7.8	98.0
4	22	2.0	100.0
Total	1095	100.0	

On x2 statistics, there is no significant association between use of these substances and the outcome, p=.056 OR: 1.449 (.990, 2.122) for tobacco, p=.605 , OR: .924 (.685, 1.247) for alcohol, p=.768, OR: 1.048 (.768, 1.429) for soft drugs and p= .302, OR: 1.531 (.678, 3.460) for hard drugs. Number of substances used did not show statistical significance on X2 test, p=.163 nor did any substance use, p= .659, OR: 1.063 (.811, 1.393).

Table : Statistical tests (P ,OR, CI) for adherence concerns

Variablre	P	OR	CI
Stigma	.975	1.013	.626, 1.640
Afraid of meds	.789	.928	.536, 1.606
Dought that medications will work	.329	1.946	.641, 5.906
Depressed/Anxious	.782	1.291	.402, 4.147
Will forget to take medications	.03	1.484	1.037, 2.124
Any concern(No/Yes)	.021	.717	.540, .952
Number of concerns	.078	.804	.631, 1.025

Table : statistical tests (P, OR, CI) for disclosure

Variable	P	OR	CI
Husband/wife	.105	1.332	.941, 1.887
Brother/sister	.052	1.376	.996, 1.900
Parents	.681	.929	.652, 1.322
Own children	.917	.976	.616, 1.547
Relatives	.929	.981	.638, 1.507
Friends	.726	1.081	.699, 1.670
Any disclosure(No/Yes)	.001	.653	.502, .848
Number of persons disclosed to	.031	.815	.677, .981

Table: Incidence rates of loss to follow up at specific cohort times after start of ART, June 2009, St Peters Hosp, AA

Cohort	person-time	failures	rate/p/day	[95% Conf. Interval]	
(0 - 30]	27213	143	.00525484	.0044604	.0061907
(30 - 60]	23796	44	.00184905	.001376	.0024847
(60 - 90]	21795	25	.00114705	.0007751	.0016976
(90 - 120]	20747	18	.0008676	.0005466	.001377
(120- 150]	19733	24	.00121624	.0008152	.0018145
(150- 180]	18881	20	.00105927	.0006834	.0016419
(180- 365]	105654	47	.00044485	.0003342	.0005921
> 365	213818	48	.00022449	.0001692	.0002979
Total	451637	369	.00081703	.0007378	.0009048

Table : Correlation between variables to be included in the multiple cox regression model

	age	educational status	religion	children at home	care giver info	weight	functional status	who stage	c st
Age	1	-.090(**)	-0.012	-.305(**)	-.085(**)	.214(**)	0.009	0.012	
educational status	-.090(**)	1	.111(**)	.093(**)	-.162(**)	.232(**)	-.114(**)	-0.045	- .0
religion	-0.012	.111(**)	1	0	0.016	0.002	-0.046	-0.001	
children at home	-.305(**)	.093(**)	0	1	.192(**)	-0.05	0.061	.071(*)	
care giver info	-.085(**)	-.162(**)	0.016	.192(**)	1	-.063(*)	.064(*)	.079(*)	
weight	.214(**)	.232(**)	0.002	-0.05	-.063(*)	1	-.331(**)	-.182(**)	.1
functional status	0.009	-.114(**)	-0.046	0.061	.064(*)	-.331(**)	1	.365(**)	- .2
who stage	0.012	-0.045	-0.001	.071(*)	.079(*)	-.182(**)	.365(**)	1	- .2
cd4 at start	0.052	-.079(**)	-0.002	-0.038	-0.009	.193(**)	-.257(**)	-.215(**)	
initial regimen	0.022	0.023	0.015	.068(*)	-0.01	.119(**)	-0.009	.110(**)	.0
Understand HIV disease	-.082(**)	.371(**)	0.051	.085(**)	-.076(*)	.147(**)	-.151(**)	-0.044	
Understand HIV transmission	-.075(*)	.329(**)	0.047	0.022	-.094(**)	.194(**)	-.213(**)	-.071(*)	
disclosure to spouse	-0.004	-0.051	0.016	.221(**)	.137(**)	-.086(**)	.063(*)	0.038	
forgetfulness	-0.023	-.075(*)	0.013	0.028	0.019	-0.047	0.042	0.026	
Any concern	0.01	.108(**)	0	-0.046	-0.039	0.016	0.034	0.025	
Disclosure Status	0.021	.111(**)	-0.025	-.076(*)	-.276(**)	0.004	0.002	-0.007	

Appendix 3: Consent form

Assessment of the Magnitude and Factors Associated with Loss to Follow up in the ART Program of St. Peter Hospital, Addis Ababa

Informed consent form to participate in in-depth interview

You are being asked to participate in a research project to evaluate the magnitude of problem of discontinuation of ART in Addis Ababa and why this happens. This research is being carried out in two public Hospitals of Addis Ababa, ALERT and St Peters Hospital.

If you agree to participate in this study, you will undergo an in depth interview about your experience in HIV, ART treatment and why people discontinue ART. You will be interviewed only once and the interview might take about an hour.

There is no harm to you in participation, except may be a slight chance of someone else finding out your information. But I will try very hard to protect you against this risk. We will not use any names or any information that can be used to identify you. All the documents will be place in a secure place.

There are no direct benefits to you of participating. But the findings from this study will be used to improve care of people living with HIV in Addis Ababa and Ethiopia. You may be reimbursed for your transportation expenses.

Participation in this research is completely voluntary. You may also opt not to participate and it will have no effect.

For questions about this research and related issues, contact _____

I have read the above consent form/ the above consent form ha been read to me; I have fully understood its contents and I consent to participate in this research project (In-depth interview).

Name of participant _____ Signature_____ Date_____

Name of interviewer _____ Signature_____ Date_____

Name of witness _____ Signature _____ Date _____

Appendix 4: Consent form Amharic version

¾È[›?‹ ›Ãy? I¡U“ Ts[Ø SÖ<’<“ U¡”Á„‹

¾õnÅ˜’ƒ T[ÒÑÝ pê

u›.› ¨<eØ ¾È[›?‹ ›Ãy= I¡U“” Ts[Ø ÁK¨<” SÖ”“ U¡”Á„‡” uT>ÁÖ“ Ø“ƒ }doò ›”Ç=J’< ðnÅ˜’ƒ-” KT¨p ÃI ØÁo k‘xKAoM :: ÃI Ø“ƒ uG<Kƒ ¾›.› ¾S”Ócƒ Jeú ‹ (¾›K‘ƒ“ pÆe ä¨<KAe) ¾T>‰H@É ’¨<::

u²=I Ø“ƒ KS"ðM Ÿ}eTS< ØMp nKSÖÃp ÃÅ[ÓM- M:: eK ›?‹ ›Ãy=“ eK È[›?‹›Ãy= I¡U“ ¤KAƒ MUÉ” Á"ƒoM:: nK SÖÃl ›”È w‰ ¾T>"H@É c=J’ ¨Å ›”É c¯ƒ ›"vu= K=¨eÉ Ã‹LM::

unK SÖÃl S"ðM ¾T>ÁÅ‘c¨< Ñ<Çƒ ¾KU:: T“Mvƒ ¾‘e- S[Í uK?L c¨< ¾So¨p ›’e}— †ÉM K=•` Ã‹LM:: ’Ñ‘ Ó” ÃI †”ÇÃJ” Ÿõ}— Ø”no ÃÅ[ÒM:: unK SÖÃl eUU J’ †‘e-” KT¨p ¾T>Áe‹K< S[Í-‹” ›”ÖkUU:: u}ÚT]U ¾nK SÖÃl”“ K?KA‹ S[Í-‹ ¾Á²< që‹ uS<K< uØ”no ÃkS×K<::

uØ“~ uSX}õ ¾T>ÁÑ–<ƒ kØ}— ØpU ¾KU:: ’Ñ‘ Ó” ¾Ø“~ ¨<Ö?ƒ u›.›“ u›=ƒÄåÁ Ÿ›?‹ ›Ãy= Ò‘ KT>’•\ ¾T>[Ñ¨<” IŠU“ KThhM Ã[ÇM:: KSÕÕ¹ KT>¤¨¸ƒ ¨¾ ÃŸðKA}M::

u²=I Ø“ƒ SX}õ S<K< uS<K< uõnÅ˜’ƒ LÃ ¾}SW[} ’¨<:: uØ“~ FKSX}õ u=¨e’< U”U ¾T>ÁS×w- ‹Ó‘ ¾KU::

eK Ø“~“ }ÁÁ» Ñ<ÇÄ‹ ØÁo "K-ƒ ---------- Á’ÒÓ\”::

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Appendix 5: Interview guide

1. Introduction and warm up questions
2. What made you think of getting tested for HIV and when was that?
3. After you got tested and knew that you have the virus, were there any problems to go to a health facility or to start ART?
4. When you started ART, were there any concerns that you thought will make it difficult for you to take the medications appropriately?
5. How was your understanding and attitude towards ART when you started the treatment?
6. Did you face any problems because you are taking ART?
7. If you have discontinued ART, can you tell me why you did so and after how long treatment? What do you think are the common reasons that make people discontinue ART?
8. Did you face any problem because you discontinued ART?
9. What do you think should be done to support PLH not to discontinue ART?
10. Any other thing you want to add?

Thank you

Appendix 6: HIV care /ART intake form, Federal Ministry of Health, Ethiopia (see accompanying file)

Appendix 7: HIV care /ART Follow-Up form, Federal Ministry of Health, Ethiopia (see accompanying file)